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AUTHOR Potts, Patricia
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ABSTRACT

One of 16 booklets designed for use in an Open University course on the education of handicapped students in the United Kingdom, this document considers biological factors involved in handicapping conditions. An initial chapter examines the portrayal of disabled persons in drama, literature and film. Genetic involvement (autosomal dominant inheritance and recessive inheritance) is considered. Educational implications of children with hearing impairments and epilepsy as well as children whose physical condition requires the use of special equipment and personnel are analyzed. Similarly, the implications for children who are categorized according to syndromes such as autism, dyslexia, and hyperactivity are reviewed. The involvement of the medical profession in education is the topic of another section. A conclusion asserts that medicine's role in the education of most children with disabilities should be limited. (CL)

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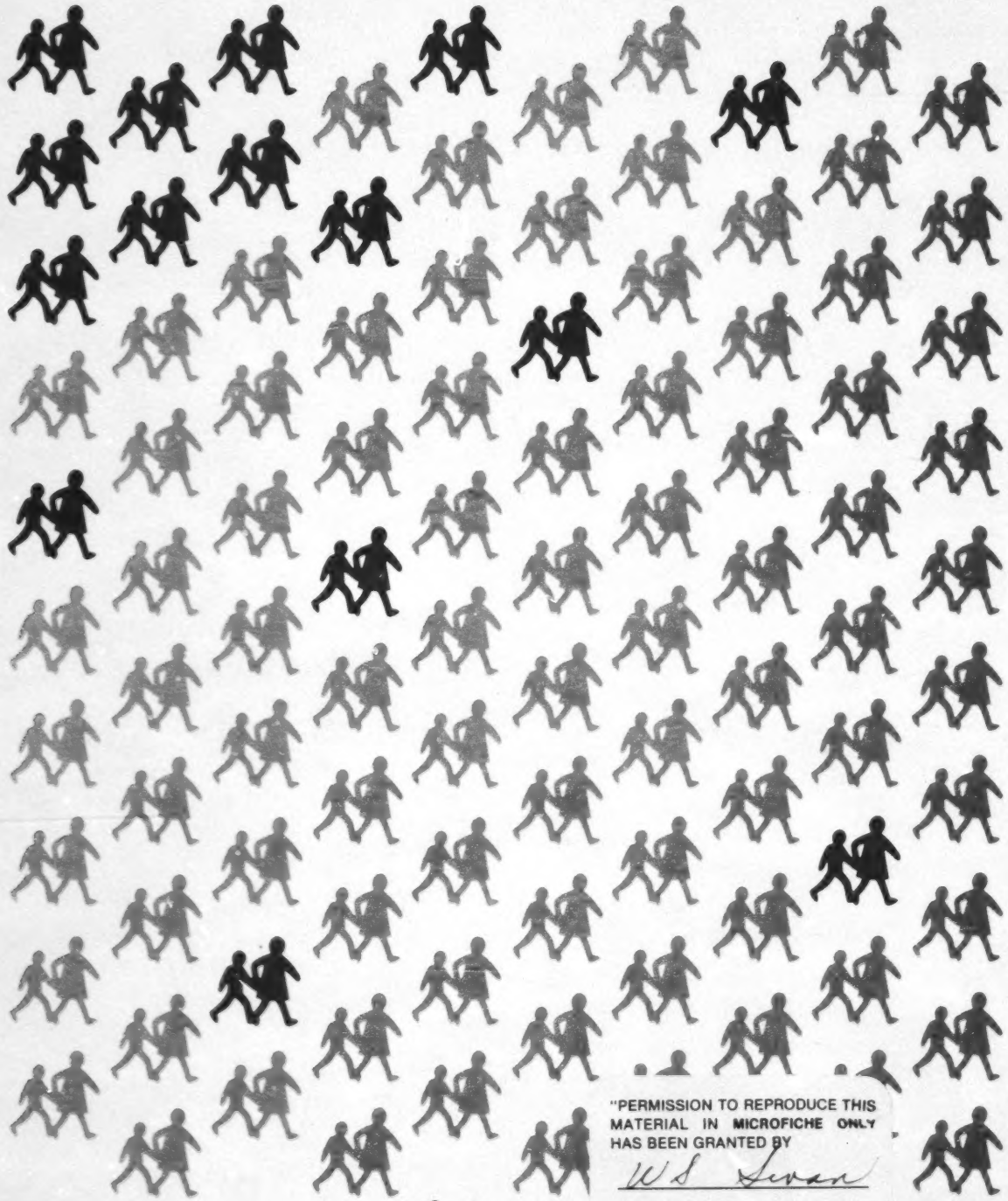
The Open University
Educational Studies: A Second Level Course
Special Needs in Education

ED235620

BIOLOGY AND HANDICAP



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The Open University
Educational Studies: A Second Level Course
E241 Special Needs in Education

Unit 11
Biology and handicap

Prepared by Patricia Potts for the Course Team

The Cripples, by L. S. Lowry. Lowry said of this picture, 'People just don't use their eyes, you know. Now take this, my friends are always arguing that I just couldn't have seen as many cripples as that. Well, of course, I didn't see them *all* at once, but I have seen them all from time to time and here, in this picture, I have simply brought them all together.'

The Open University Press

The E241 Course Team

Julie Barnfather (secretary)
Carolyn Baxter (course co-ordinator)
Tony Booth (author)
Nick Brenton (BBC producer)
Dennis Briggs (author)
Jim Burge (BBC producer)
Ronnie Flynn (research assistant)
Chris Gravell (editor)
Euan Henderson (IET)
Audrey Lambart (staff tutor)
Rob Lyon (designer)
Kathy Morris (liaison librarian)
John Pettit (editor)
Keith Pocklington (author)
Patricia Potts (author)
Chris Pym (reading member)
Sue Sheldon (course manager)
June Statham (case studies author)
Andrew Sutton (author)
Will Swann (author)
David Thomas (author)
Richard Tomlinson (author)

External assessors

Seamus Hegarty
Philip Williams

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Reading

Set reading

The readings for this unit are to be found in:

SWANN, W. (ed.) (1981) *The Practice of Special Education*, Oxford, Blackwell/The Open University Press (the Reader). They are:

GOLDING, J. (1981) 'Physical handicap in children: sources of variation' (Reading 1.3).

CHAZAN, M., LAING, A., SHACKLETON BAILEY, M. and JONES, G. (1980) 'Young children with special needs in ordinary schools' (Reading 3.1).

THE LAWTHER REPORT and THE CONSERVATION SOCIETY REPORT, 'The effects of lead pollution on children's development' (Reading 1.4).

The case study for this unit is to be found in:

BOOTH, T. and STATHAM, J. (1982) *The Nature of Special Education*, London, Croom Helm/The Open University Press. It is:

' "Hyperactive" children' (Case Study 9).

Further reading

CONRAD, P. (1976) *Identifying Hyperactive Children*, Massachusetts, Lexington Books.

ILLICH, I. (1975) *Limits to Medicine: medical nemesis—the expropriation of health*, London, Marion Boyars.

MILUNSKY, A. (1980) *Know Your Genes*, Harmondsworth, Penguin Books Ltd.

SHEARER, A. (1981) *Disability: whose handicap?* Oxford, Basil Blackwell.

SZASZ, T. (1971) *The Manufacture of Madness*, St Albans, Paladin.

Broadcasts

The broadcasts associated with this unit are Television programme 6 and Radio programmes 6 and 7. Further details will be found in the associated *Broadcast Notes*.

1 *Introduction—images of handicap*

1.1 The birth of a visibly defective human baby is always traumatic. Ignorance of possible causes (which is still common today) and the fear of punishment by the local community, the church, the state or God, encouraged beliefs in supernatural intervention as a cause of such children, whether divine (as in ancient Egypt) or satanic (as in medieval Christian Europe or Puritan North America), which thus removed the responsibility, and therefore the guilt and blame, from the mother and father. Nevertheless, deformed infants and their mothers were frequently killed because of their supposed non-humanity. In Unit 9, I mentioned some of these beliefs, including the rationalization that a deformed child was a changeling, sent by the devil as an ordeal, who, if well cared for, would earn the restoration of the parents' own child. The appearance and behaviour of severely handicapped children were taken to be more than usually obvious signs of original sin and thus confirmed the belief that the disabled in body were also defective in thought and feeling. Those who agreed with Guggenbühl that 'the immortal soul is essentially the same in every creature born of woman' (quoted in Kanner, 1964) or with Séguin that 'an idiot is endowed with moral nature and is influenced by the same things as the rest of humanity'; 'one of us in mankind but shut up in an imperfect envelope' (quoted in Ryan and Thomas, 1980) were rare. It was (and is) common to believe that the attributes of the body have parallels in the mind—wicked Richard III with a hunchback, for example—personality was inferred from physical appearance. Medieval psychology described people according to which of four fluids (humours) dominated in their blood—red-faced, red-blooded, jolly *sanguine* types, or pasty, green-tinged, envious *splenetic* specimens, and so on. The macrocosmic elements of earth, air, fire and water all had microcosmic correspondences in the bodily juices and personality of each human being. When the chemical balance was upset, physiology and character were both affected. The root of the insult to disabled people, however, lay in them being deprived of their status as human beings.

1.2 In *The Times* (26 May 1980) Charles Hargrove wrote a horrifying report of the trial of an ageing priest who ran a home for mentally handicapped children near Montpellier and was accused of assault and manslaughter. An epileptic girl, aged 13, died of suffocation while hanging from a wall in a straitjacket in a padded cell—she had made noises during Mass. Children were hit with spoons, dragged downstairs, tied to hot radiators and plunged face down into lavatories, but the priest remained entirely unrepentant: 'The conditioning of the mentally handicapped by violence is necessary to compel them to acquire a sense of responsibility'; 'Handicapped children are not like others. They want to be, but do not have the will. They must be compelled through fear and punishment.'

1.3 Bri, father of 'Joe Egg' in Peter Nichols's play (1967) is desperate rather than sadistic, but so desperate that he leaves his mentally and physically handicapped daughter lying on the back seat of the car while it is snowing just after she has had a whole series of convulsions, in the hope that the cold will kill her. Bri is sarcastic about his wife, Sheila's, feelings of guilt:

> *Bri* Sheila's got a theory about Joe's birth. She doesn't blame the doctors. She blames herself.
>
> *Bri* It was because she choked it back.
>
> *Bri* Because she'd slept around.
>
> *Sheila* I think it was partly because I'd been promiscuous, yes, and my subconscious was making me shrink or withdraw from motherhood.
>
> *Bri* She was on the way before we married. That feeds the furnace of guilt.
>
> *Bri* Nurse, nurse, we've done it, I tell you! With this we can make whole continents barren. The deterrent they've all been working for.

Sheila is more accepting, or resigned:

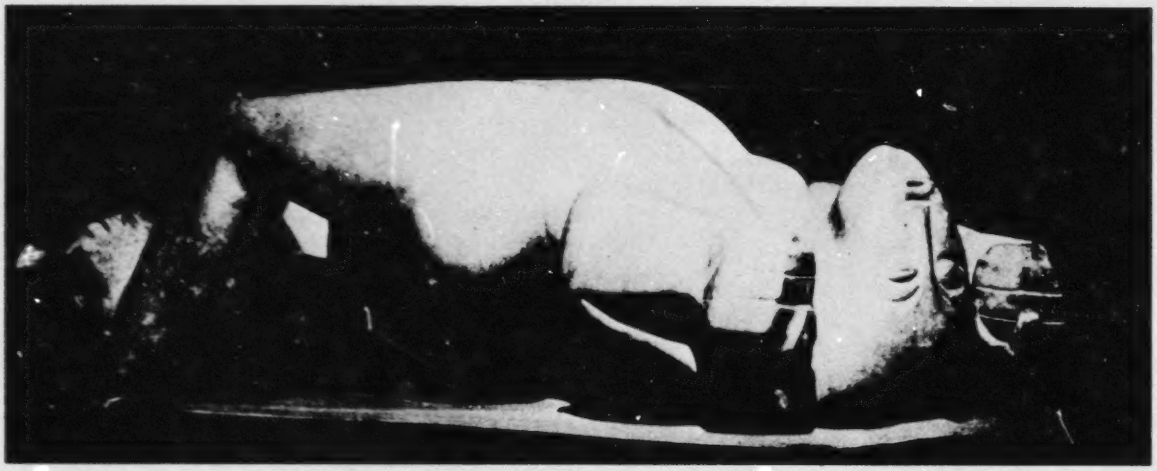
> Watching somebody as limited as Joe over ten years, I've begun to feel she's only one kind of cripple. Everybody's damaged in some way. There's a limit to what we can do.

1.4 Sarah, mother of grown-up, respectably employed, mentally retarded Walter in David Cook's novel, is usually in tight control. But when her son arrives home from work on the day her husband dies and asks for him, the effort to stay in control is almost too much for her. Walter clings to her for security and at this Sarah breaks down, weeping for her own imprisonment:

> He watched her, silent now and still, feeling the darkness at the base of his stomach grow. This was the feeling he recognized as fear; his vocabulary was not yet so wide as to include the word, but he knew the feeling well; it was what you felt just before a scream burst out of you. His mother was not in control, and he was frightened. The feeling was getting worse, and she wouldn't look at him, wouldn't help him, hold him, even for a moment touch him. He pressed himself against her, clutching at her blouse, his arms around her waist. She was struggling to free herself, shouting at him to let go, protecting her face from his greasy, spotty, anxious, animal's face, fighting off a son who was taller, stronger than she, whose head was a weight on her shoulder, and whose need to be cuddled made her sick.
>
> As she pushed him away, flaying around wildly with her arms and shouting between sobs, he started his scream. It was a long continuous earsplitting scream of terror, punctuated by the stamping of his feet. As he topped up with breath so as to make the scream persist, he bit the back of his own hand. She rounded on him, first striking him across the face, then gripping the hair at the back of his neck, pulling him towards the sink, and pushing his head under the cold-water tap.
>
> He made no resistance after her slap across his face. The fact that she had taken control relieved much of the fear he felt. The cold water struck the back of his head; he felt it slide down the sides of his face and neck, and wet the collar of his shirt. His body relaxed. He watched the water run from the end of his nose into the sink, and circle the plug-hole, and concentrated on the feel of it. Sarah was pressing his neck to keep his head down, but since he did not resist, she loosened her grip, then removed it, and reached for a drying-up cloth.
>
> Walter remained obediently where he was, with his head under the tap, until she turned off the water, placed the drying-up cloth over his head, and guided him into the living-room.
>
> She sat on the settee, and Walter lay on it in the foetal position, with his wet head resting in her lap. She moved the drying-up cloth slowly and gently back and forth to dry his face and hair. After a while she said, 'Your dad's gone to sleep for a very long time. We won't see him again, until we fall asleep forever. Then we'll meet him again, where and when God wants us to. It's hard for you to understand, I know. But even though we shall miss him . . .'
>
> She could not go on. She would not miss Eric; her tears were not for that. All through her married life until now, she had still preserved some thoughts, some hope of freedom, or at least of relief. Now Eric had found that freedom; he had relief. Her tears were for herself, not her husband. She was trapped, still trapped, forever trapped with a twenty-seven-year-old-late-developer. It was comic. Here he lay on her lap, this *thing* she had made. From now on, she was totally responsible for Walter. The trap had tightened; the wire round her neck was pulling. She was like a rabbit which hadn't the sense to draw back while the noose was still slack. If only she had left, run away all those years ago, used her mother's jewellery to go somewhere, anywhere at all! If! The head in her lap moved, and she must speak to it.
>
> 'Even though I know you'll miss him a lot, you've got to remember that he's happy now, where he is. He has no problems, you see. You must be glad for him. We all have to fall asleep some time, but when we do, it's a sleep of peace. Jesus calls us to him, and we are glad to be called. That's the day of Reckoning. You fall asleep, and Jesus decides if He wants you to live with Him in Paradise. Only those who have been good get to live forever with Jesus. We won't see your dad any more, but Jesus will look after him.'
>
> Gently she began to rock Walter's head, so that his whole body moved backwards and forwards. His wet hair had left a damp patch on her dress. It would dry out. If she rocked him for long enough, she might be able to convince herself as well as her son of the truth of what she had just told him. She had to. There had to be a point to it all. There must be some compensation for life; that was only fair. She began to sing.
>
> (Cook, 1980, pp. 98–9)

1.5 An increasing number of plays, films, novels, television documentaries and consumer radio programmes are concerned with disability and handicap. Does this mean that attitudes have changed, that there's a prevailing acceptance of disability as an ingredient of everyday life? Stigma is attached to various disabilities in changing proportions, but it is still strong. Advertising posters are still very sentimental; segregation reflects contemporary fears. Films such as *The Elephant Man*, Truffaut's *L'enfant Sauvage* and Herzog's *The Enigma of Kasper Hauser* portray characters permanently isolated by physical and social disabilities, presenting images and behaviour that could easily disgust, but somehow they do not. These works of art keep their distance, deflecting attention from the multitude of more roughly-hewn works of life.

Nabil Shaban, a young man with brittle bones and a leading actor with the Græ Theatre Company.



Jacob Epstein's A Woman Possessed.

9

1.6 But before speeding, polluting vehicles drove daily life off the streets, experience of disability was commonplace:

> At Finsbury Park my brothers and I had grown accustomed to the presence of idiots in the streets, and without in the least understanding it, had accepted that there were strange grown-ups who publicly behaved in much the same zany fashion as we did when we wanted to make each other laugh.
>
> (Rolph, 1980, referring to about 1910)

1.7 Today, the arts and the media are continually exposing and publicizing disability. Does this mean that there is a new awareness, an acknowledgement, or candour about prejudice? Journalists in the position of informing us about the lives of the disabled, however, are caught in an inevitable trap: they report with sympathy, disseminate information to the ignorant, and forcefully advocate measures that would secure a 'normal', 'ordinary' life for their subjects. But the force of their advocacy often lies in exaggeration, sensationalist writing designed to make us sit up and take notice:

> [There is now growing evidence of a firm link between poor educational attainment and even quite low levels of lead pollution in children . . .] One key effect can be reduced IQ. A recent study puts the potential drop at up to five per cent, which can double the number of British children reckoned to be mentally retarded.
>
> (Rick Rogers, *New Statesman*, 3 April 1981)

1.8 This exaggeration is particularly evident when cases of children disabled as a result of medical incompetence are reported. In order to win the maximum compensation, the severity of impairment has to be stressed, the contrast between 'before' and 'after' brought into sharp focus, and prophecies of a vegetable future spelled out. Disability's associations with subhumanity are thus strengthened rather than weakened. Its biological nature and irreversibility are emphasized, and the concrete, physical nature of handicap predominates.

1.9 Biological knowledge of human disabilities is of defects in organic structures or processes, together with their causes, incidence and continuing prevalence. Biological knowledge is of the physical impairment, not of the social handicap.

1.10 The child with a physical impairment, however, is a person, not a body plus a mind, and is very likely to experience handicap as a result of the disability. What happens to people's bodies may well influence their minds, just as what people think and feel will affect their bodies. Biological knowledge can contribute to an understanding of children with disabilities and thus is relevant to those who work with disabled children in social institutions, such as schools.

1.11 But there are limits. In this unit I shall try to show, first, that the biological basis of the difficulties facing many children in schools, while necessitating medical help, does not justify extensive medical control in special education; and second, that ignorance of the causes of intractable problems faced by teachers does not justify the assumption of hidden physical damage.

1.12 In section 2 there is a discussion of the variety of factors that can lead to physical, mental or sensory impairment, the biological basis of handicap. In section 3 I ask what the educational implications are of this biological knowledge, how disability influences school placement, and whether it should. In section 4 I look at autism, dyslexia and hyperactivity: what are the justifications for believing that these labels refer to biologically abnormal conditions and how could these assumptions be helpful to teachers? Do they reinforce the idea that handicap is a physical, individual problem, agreeably deflecting attention from the social context in which these problems arise?

1.13 In section 5 I look at the involvement of the medical profession in special education, making a distinction between the positive contributions of doctors to the welfare of children with disabilities and their illegitimate control of educational assessment. In the concluding section I discuss the relationship between the biology of disability and the concept of 'special educational need' which has now replaced the 1944 Education Act's categories of handicap (see pp. 57-8 of Unit 1/2) and which is officially intended to minimize the exclusion of children from ordinary schools because of disability.

1.14 The *Glossary* contains a brief description of the disabilities discussed in this unit and elsewhere in the course, and is designed to complement the units. I shall refer to it specifically from time to time, but you are encouraged to keep it by you as you work through this unit.

2 *The biological basis of handicap*

2.1 A great variety of hereditary, congenital, environmental and unknown factors can result in physical, mental or sensory disabilities. Damage to a person's anatomy or bodily processes may be visible or invisible and may or may not turn out to be handicapping in terms of education, mobility, employment or social life. Although we do not know nearly enough to be able fully to describe and explain all physical impairments, an account of such an impairment necessarily involves biological knowledge, either of its causes or its effects, or both. Because so many people with disabilities are forced to lead restricted lives, it may therefore be said that biological knowledge is relevant to the understanding of handicap. But this is only true indirectly, and only when a person's disability in itself precludes ordinary participation in community life and cannot, for the moment, be overcome by aids, therapy or the acceptance of others.

Genetics

2.2 An example of heredity working to produce damaged bodies is the transmission of physical and mental characteristics from parents to offspring via harmful genes, and there are several ways in which this may happen: autosomal dominant inheritance, recessive inheritance, sex(X)-linked recessive inheritance and sex-linked dominant inheritance (not transmitted via the X (female) or the Y (male) chromosomes).

2.3 The 46 chromosomes in each human cell (except for the sperm and ova, which each contain 23) consist of 22 pairs of 'autosomes', numbered in decreasing order of size, and two separate 'sex' chromosomes, XX in a female and XY in a male (see Figure 1, below and overleaf). The chromosomes are composed of millions of chemical 'genes', made up of strands of DNA, and in everyone there are some that are potentially harmful.

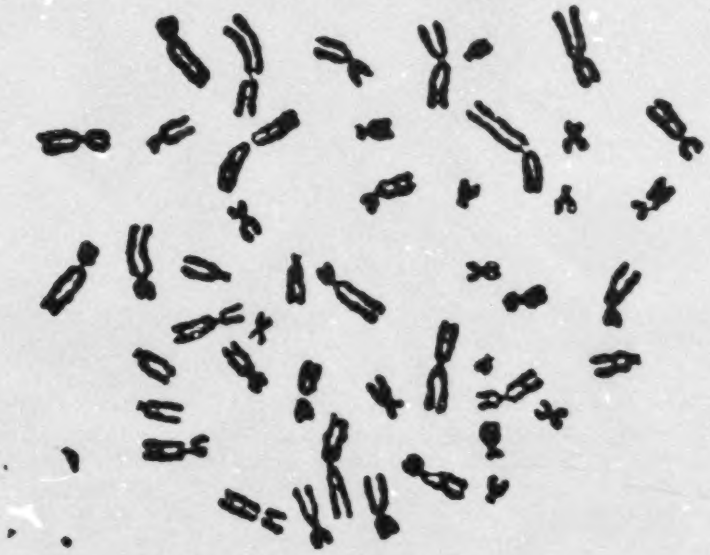


Figure 1 (a) The 46 chromosomes from a single male cell.

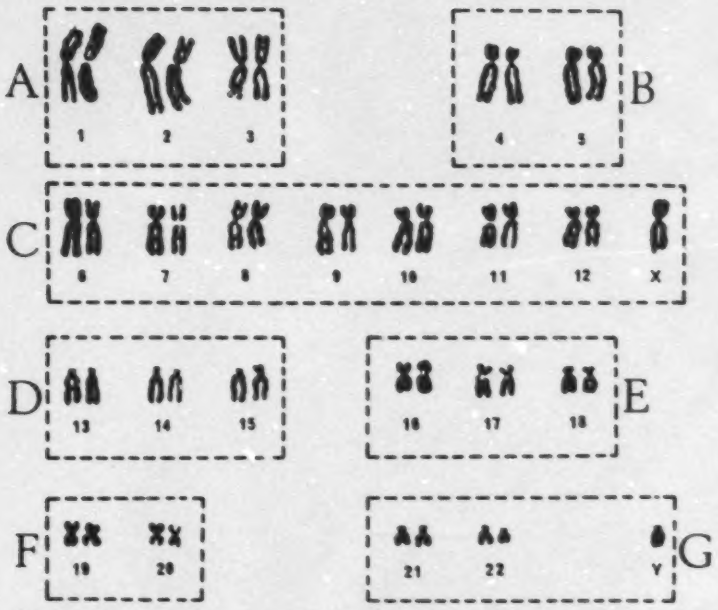


Figure 1 (b) The chromosomes are arranged and numbered by convention, in decreasing order of size, as shown here. The X and Y are not numbered.

Autosomal dominant inheritance

2.4 In a pair of chromosomes the genes are arranged so that there is a gene at all the same points (*loci*) on each chromosome. But, while the loci are matched, the genes themselves are not necessarily identical. A 'dominant' gene, for example, is one that is stronger in its action than its located partner and which can therefore suppress the activity (in effect the 'message') of that partner. When the dominant gene is harmful the possessor (male or female) will be affected and will pass the disease to 50 per cent of his or her offspring. Half the children will be unaffected because they will have inherited the normal partner gene rather than the dominant, harmful gene (Figure 2). Examples are achondroplasia (dwarfism), and Huntington's chorea (a disease of the central nervous system which may not develop until quite late in adult life and, therefore, often *after* the sufferer has had his or her children).

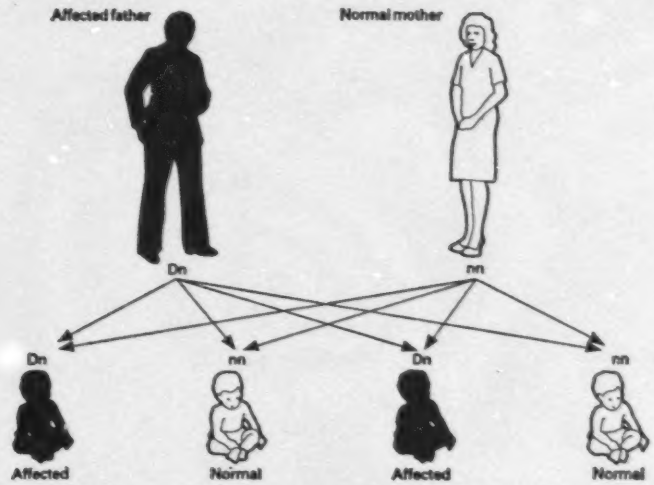


Figure 2 Autosomal dominant inheritance. One affected parent (of either sex) has a defective gene (D) that dominates its normal counterpart (n). Every child has a 50 per cent chance of inheriting the defective gene D (and will then have the disease) or the normal gene n from the affected parent.

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Recessive inheritance

2.5 A person may carry harmful genes and not suffer any disability. In this case, the harmful genes are 'recessive' and, if paired with a healthy gene, are suppressed, their effects being reduced to a barely detectable and certainly not disabling level. For a child to be affected by disease carried on recessive genes, *both* parents must be carriers (see Figure 3). Cystic fibrosis and phenylketonuria are examples of recessively-inherited genetic diseases.

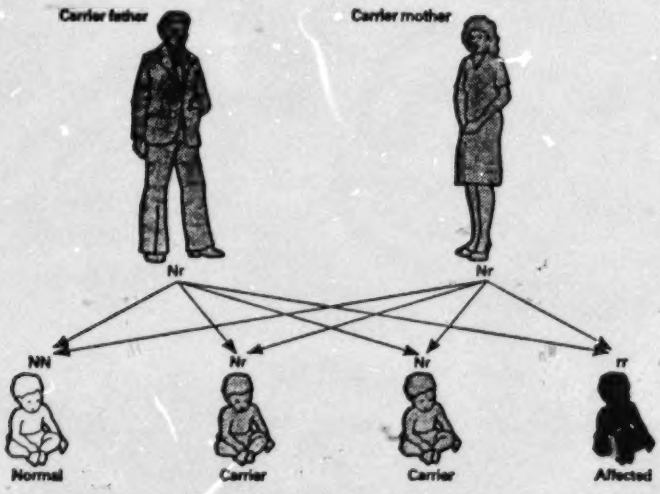


Figure 3 Recessive inheritance. Both parents are usually healthy, but each carries a defective gene that by itself generally causes no problems. Disease follows when a person receives two of these recessive genes. There is a 25 per cent chance that a person will inherit a double dose of the defective gene; a 50 per cent chance of being a carrier; and a 25 per cent chance of being neither a carrier nor affected.

2.6 Defective genes are fairly often carried on a female X chromosome but never (so far as it is known) on the male Y. Sex (X)-linked recessive inheritance of genetic disorders, therefore, occur when only the mother is a carrier of the disease (Figure 4). None of her daughters will have the disease because either they will have inherited a healthy X chromosome from both parents, or the defective gene from the mother will be suppressed by a healthy X from the male. But 50 per cent of her sons will be affected by the disease if their only X chromosome contains the defective gene; 50 per cent will be healthy, not even carriers. Haemophilia and muscular dystrophy are examples of X-linked diseases, in nearly all cases of which only males are affected and only females carriers.

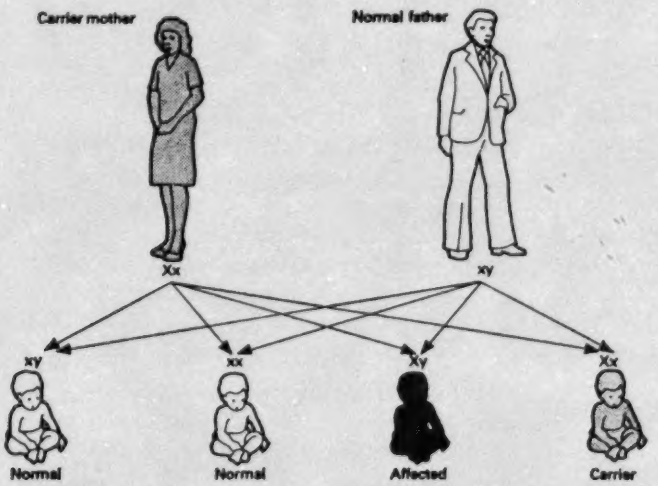
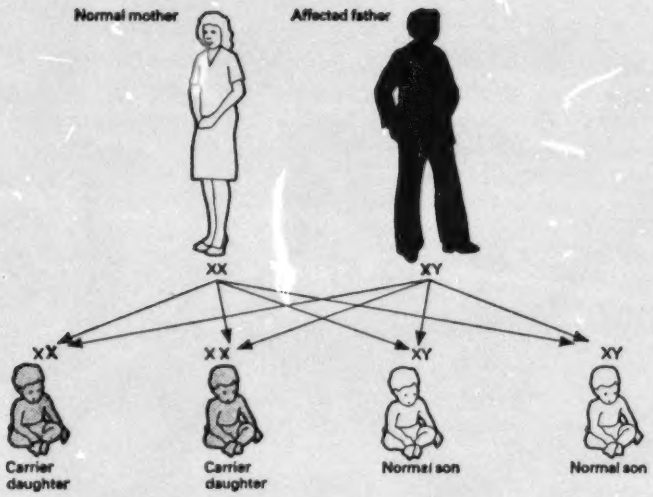
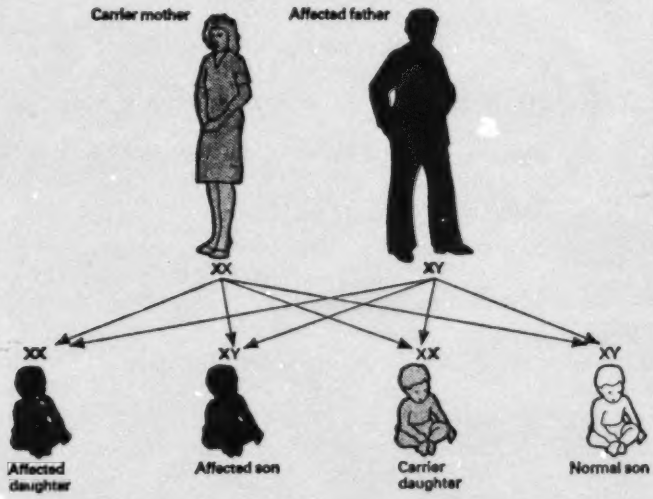


Figure 4 Sex (X)-linked recessive inheritance.
(a) The defective gene is carried on one X chromosome of the mother, who is usually healthy. Disease follows when that X chromosome containing the defective gene is transmitted to a male. The odds for each male are 50/50 for being attacked, and for each female child 50/50 that she will be a carrier.

13



(*b*) *Sex (X)-linked inheritance.*
The defective gene on the X chromosome is on the father's X. He has the disease (e.g. haemophilia). He passes his X chromosome to all his daughters, who become carriers, while none of his sons are affected.



(*c*) *Sex (X)-linked inheritance.*
The defective gene is present on the X chromosome of the father and on one of the X chromosomes of the mother. The father has the disease (e.g. haemophilia) and the mother is a carrier. This time there is a 50 per cent chance that a daughter will be affected, and a 50 per cent chance that a son will have the disease.

2.7 However, not all genetic abnormalities are inherited. Many congenital (from birth) defects are the result of spontaneous mutation when something goes wrong with the gene-reproducing process, usually for no known reason (the parents are quite healthy) but possibly after a virus infection or exposure to X-rays. Ninety-six per cent of Down's Syndrome children do not inherit the condition from defective parental chromosomes. And there are environmental influences that may combine with genetic factors to produce conditions such as cleft palate, spina bifida, and anencephaly.

2.8 Advances in medical knowledge and treatments could have the paradoxical effect of both increasing and decreasing the births of genetically disordered children. More sufferers can survive to become parents and so transmit their disorder, but also more sufferers (and carriers) can seek genetic counselling and either choose not to have children as a result or take the risk and rely on pre-natal screening by techniques such as foetoscopy and amniocentesis to indicate when the foetus is defective, or on examination at birth for phenylketonuria. (See section 5 for a discussion of genetic counselling and see the *Glossary* for information about chromosomes, genes, foetoscopy, amniocentesis, haemophilia, etc.)

Reading Now read 'Physical handicap in children: sources of variation' (Reading 1.3).

Comment Jean Golding makes clear the distinction between the 'incidence' and 'prevalence' of a disability in the population, and discusses a range of factors which influence variations, such as time, place, occupational class, age of parents, diet, birth order, sex of child, smoking, drugs, and genetic inheritance. Also, compare her statistics with those given in Figure 5, which shows the prevalence of disabilities in one PH school in Greater London. The picture is complex and volatile, and Jean Golding argues that, while the preventation of disability may be a laudable aim, it remains largely elusive.

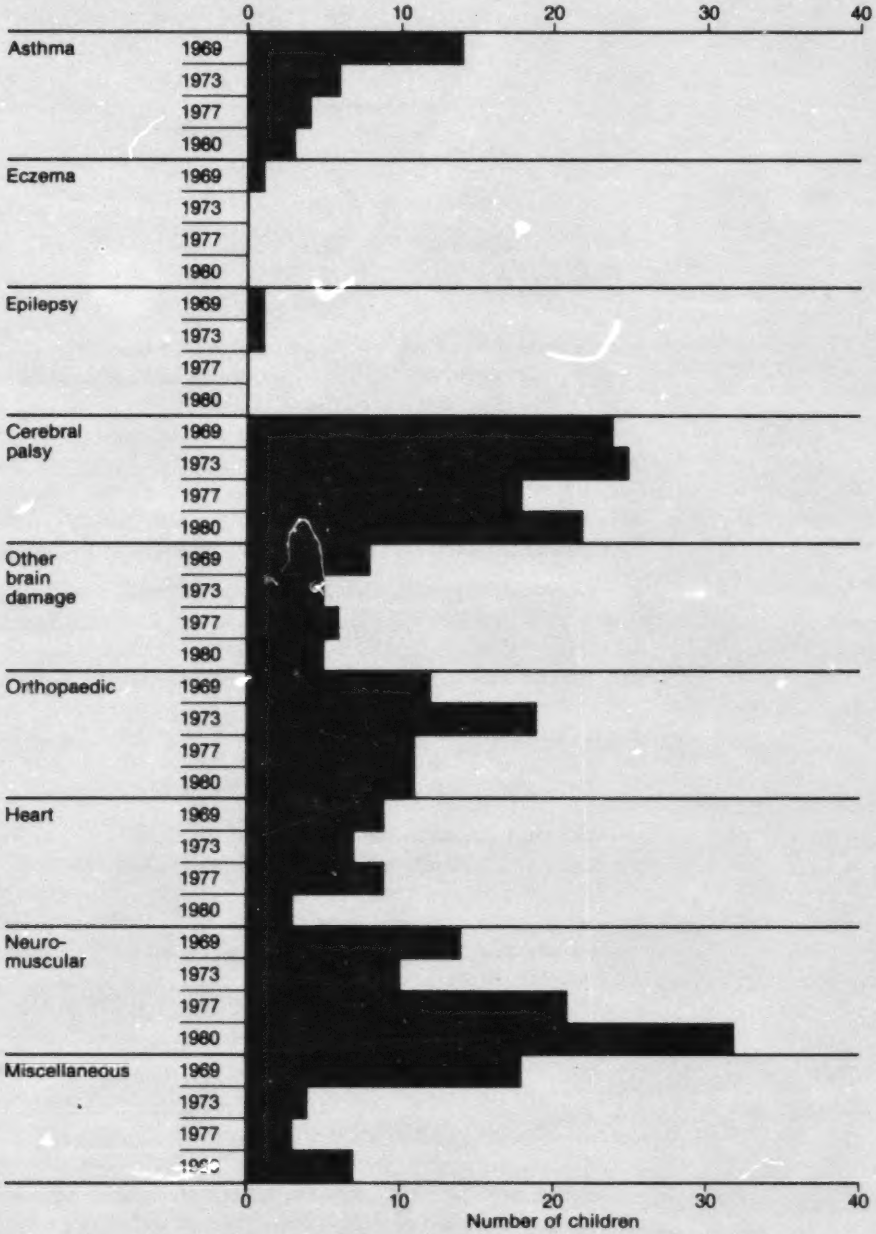


Figure 5 Proportion of disabilities in one school for the physically handicapped in a Greater London Borough (from information supplied by Doreine Bates, an Open University PhD student).

15

The language and tone of the article, however, are very clinical, with a whole range of disabilities and problems described as 'lesions' or 'traumas', as if sex-role stereotypes, infectious and congenital defects were all the same kind of influence, and as if medical diagnostic terms were objectively factual.

The reality of social class differences in the incidence of physical impairment, when described in this detached way, makes me think of the old belief in the inevitable association of poverty with defective births, reprehensible social habits and irresponsibly large families. These problems are social, not biological. And if the job of the husband, on which social classification is based, turns out to be irrelevant to the incidence of problems, then isn't the whole system of classification undermined? It certainly omits a large group of people whose problems are enormous and who could not be represented in the present system, namely single mothers.

If social class is as potent an influence on the incidence of disabilities in children as the evidence suggests, then plans for prevention must include attacks upon prejudice, poor housing and unemployment alongside research into genetic inheritance or pre-natal screening.

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3 *The educational implications of biological knowledge*

3.1 In section 5 of Unit 5/6, Will Swann argued that biological knowledge of a child's disability was, by itself, no guide to what that child was like and could have no implications for schooling unless it consisted of a description of learning difficulties. A child's inability to comprehend speech and poor muscle control may cause great problems to her educators, but these are diminished in proportion as the disabilities are overcome by means of aids, physiotherapy, speech therapy and architectural modifications. Children with disabilities are often educationally handicapped by problems which are quite irrelevant to the curriculum, for example, access, incontinence and prejudice.

3.2 Many children with disabilities do not therefore need a special curriculum, and Will Swann gives examples of how, even in some special schools, they do not get one. What happens is that problems like transport, repeated absence from school, access, incontinence, lack of stamina, the likelihood of convulsions, result in a special educational *placement* for these children; provision for their bodies, but not necessarily their minds. Special resources for the education of children with disabilities may come in the form of people, materials or buildings, and, while many of them certainly do need the first two, it can be argued that only a few, if any, need their own institutions.

3.3 Obviously, teachers must be well informed about the disabilities of children they are expected to include in their classes, both about how their mobility or attention might be affected and about whether or not they are incontinent or need any minor medical attention daily. But these different kinds of biological knowledge have different kinds of implications: medical, educational, social. Children suffering from progressive disorders which could well mean sudden collapse and death when still of school age represent a responsibility that many ordinary school teachers reject. But taking an interest in a child's physical condition can also be carried too far, fascination with the disability obscuring the child as a person.

3.4 Further, there is no necessary relationship between the severity of an impairment and how difficult a teacher finds it to cope within an ordinary class. Chazan *et al.* (1980) provide evidence that severe developmental delay (manifested by language retardation and mental handicap with unknown causes) and aggressive behaviour are consistently the most problematic. The integration of children with these problems was very dependent upon the skill of the individual teacher, the adult–pupil ratio and the level of ancillary and other professional support, and much more so than that of children with sensory, physical or specific speech impairments, yet the latter are disabilities which are said to have direct implications for teaching and learning.

3.5 In *The Disabled Schoolchild* (1973), a study of older PH children in ordinary primary schools, Elizabeth Anderson also found that academic attainment was not related to severity of handicap (Anderson, 1973). It was the presence of a neurological abnormality, such as cerebral palsy or spina bifida, that consistently related to lower attainment.

Table 1 Category of handicap and academic attainment

Category of handicap	High attainment		Low attainment	
	Number	Percentage	Number	Percentage
No handicap	109	73.6	39	26.3
Congenital abnormalities including thalidomide	13	59.1	9	40.9
Spina bifida	4	33.3	8	66.6
Cerebral palsy	5	31.3	11	68.7
'Other' including haemophilia	16	66.6	8	33.3

Source: Anderson, 1973, p. 201

Table 2 Overall academic attainment and severity of handicap.

	Mildly handicapped (No. = 13)	Moderately handicapped (No. = 45)	Severely handicapped (No. = 16)
High attainment	6	24	8
Low attainment	7	21	8

Source: Anderson, 1973, p. 201.

Reading Now read the article by Chazan *et al.*, 'Young children with special needs in ordinary schools' (Reading 3.1 in the Reader). This extract from their book, *Some of Our Children*, is a detailed discussion of the experiences of integration of a group of four year olds with a wide variety of special educational needs who were placed in pre-school provision for ordinary children.

Comment Chazan *et al.* discuss each child in turn, providing you with a collection of brief, descriptive case studies which give an idea of what it was like in their classrooms. No two children's difficulties are identical, and tailoring help to their requirements shows that a combination of resources (good teachers, ancillary and other professional help, special equipment, suitable buildings, transport, and so on), adequate and shared information, and positive attitudes are all necessary.

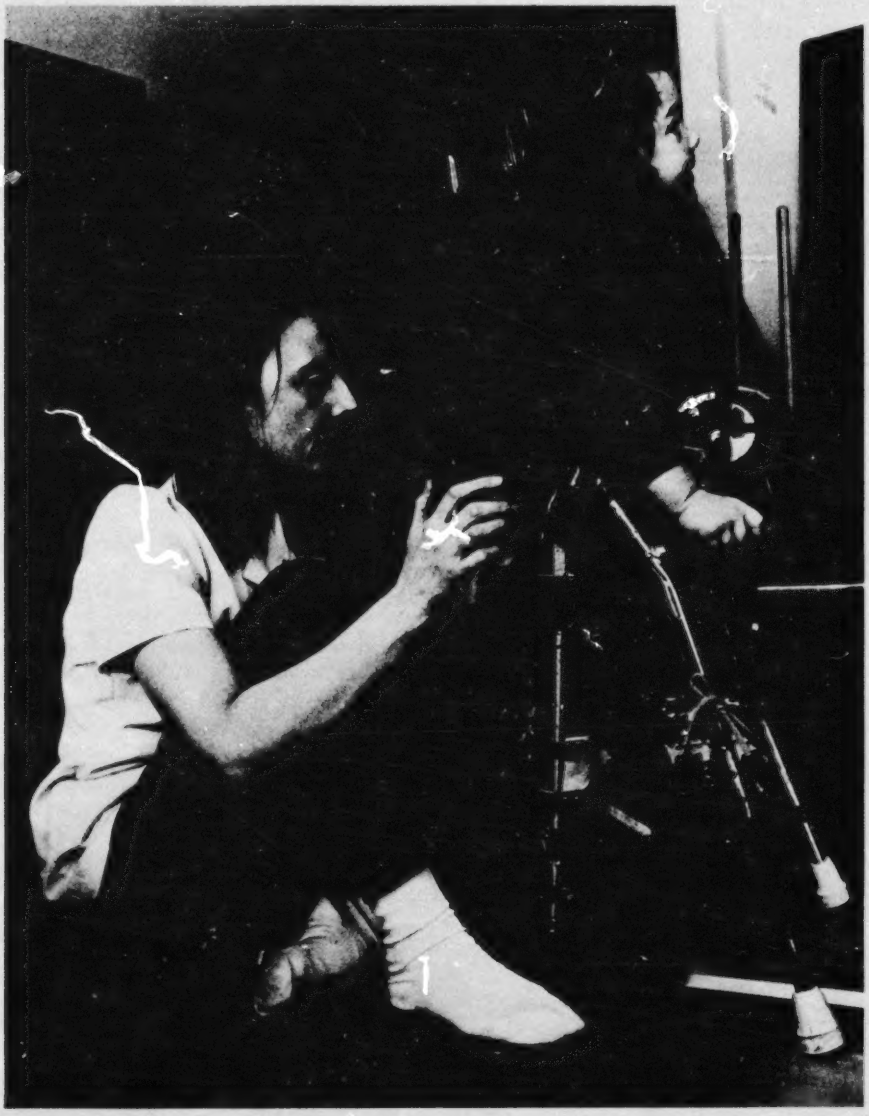
However, the approach of Chazan and his colleagues is individualistic, pragmatic, their study one of 'scientific' manipulations. Which means that judgements about integration derive, not from a moral principle, but from evidence of success or failure in particular cases: '. . . "blanket" decisions on integration are dangerous and separate consideration of each case is essential' (p. 22). Not that the writers underplay the relevance of social factors. Elsewhere in the book, they say, 'The progress of a handicapped child depends far less on the type, severity and onset of his condition than on the attitudes of his parents and on those of his peers and teachers' (Chazan *et al.*, 1980, p. 188). But they do not seem to think that these attitudes should influence school placement: 'It is important to realize that, as for any child, the relevant question is not whether a child attends an ordinary school or a special school, but rather what occurs within it' (Chazan *et al.*, 1980, p. 188). I would argue that what goes on inside and outside are closely related and that the location of provision makes a great difference.

More important, the Chazan study cuts across classification systems, showing that medical diagnoses are not reliable predictors of difficulty in school and that many problems in school are not strictly educational. But although Chazan rightly warns against the unsupported, unbriefed dumping of disabled children in ordinary schools, he takes no stand on the issue of whether or not all children should be educated together.

Aids

3.6 One problem that children with disabilities have in ordinary (i.e. large, particularly if secondary) schools is that of pace. In Unit 5/6, we saw how visually impaired children, for example, could do just as well academically as their sighted peers, except that they needed more time. Needs for aids for walking, going to the lavatory, eating, being comfortable in the classroom and overcoming very specific sensory or motor disabilities, can be met by providing space, privacy, extra funds, high technology and the imagination required to modify ordinary facilities: flexible resources rather than different curricula or locations.

3.7 However, the introduction of aids can be a delicate matter for the child and his or her family, who have to be prepared to share the problem publicly, to know whom to ask for advice and to be skilled in obtaining the funds needed, which could be considerable. Teachers, pupils, education officers, physiotherapists, speech therapists, commercial companies and social workers may all be involved. The Disabled Living Foundation and the Council for Educational Technology provide a huge range of personal and classroom equipment and respond quickly to consumer demand. Resources (and therefore disabled children) have been concentrated in special schools. Resources allocated to ordinary schools according to the demands of pupils, however, need be neither wasteful nor stigmatizing. It is the stumbling-block of pace which is harder to overcome,



Physiotherapist checking a little girl's splints.

not just because it has to do with concrete architecture and the fact that many schools and their classes are unmanagably large, but because it also raises questions about attainment, success, competition—fundamental educational values. Case study 4, 'Christopher', discussed in Unit 5/6, shows that an intelligent, sociable, incontinent child may enjoy a brief respite in an ordinary school so long as, officially, he does all the adapting. Nursery and primary school organization is often better able to respond to individual needs than that of secondary schools, and the current warnings about falling standards and competition for the few jobs left does not bode well for children who have to take life at their own pace.

3.8 Some disabilities are a handicap in education: children with sensory impairment, language and communication difficulties as a result of athetosis, or inattention due to one of the more severe forms of epilepsy, will need extra professional and/or technological help to make educational progress. And disabilities which are painful and cause frequent absences from school (such as rheumatoid arthritis—Still's disease), or which involve progressive deterioration and a poor prognosis (such as muscular dystrophy) do not initially have any direct educational implications (both arthritis and muscular dystrophy may develop when the child has already been at school for some years) but they mean decreased participation in school life, which will have serious educational consequences.

Hearing impairment

3.9 Children with poor mobility and communication skills are particularly handicapped in large schools which have a hectic timetable. There are some groups who feel that integration is undesirable because it will mean the loss of special resources, inadequate individual attention and a denial of what is unavoidably a very real disability. The debate is particularly strong among people with a hearing loss and their champions and educators. Look up 'deafness' in the *Glossary* for a description of the range of hearing impairments and their consequences.

3.10 Despair over the drastic cuts in the ordinary educational system has caused many deaf people to prefer their own special world of tailor-made, often voluntary, provision. The trouble with this entrenchment, however, is that it can mean the acceptance of the state's failure to provide a range of provision in different settings. It is also a view espoused by those who think it right for other than educational reasons to segregate disabled people. The credo of Morag Clark, head of Birkdale residential special school for the partially hearing in Southport, includes both the necessity of separate, specialist schooling and the possibility of all those with a hearing loss taking their place in open society afterwards. Her teaching is based on a 'natural' oralism in which young deaf children are educated in an auditory environment resembling that of hearing children, which does not over-emphasize visual clues and the rote-learning of artifical sentences, so common in more 'structured' classrooms, and which usually result in unintelligible speech. But you have to be patient: 'When a natural approach is adopted very little progress is seen during the early years' (Clark, 1978). However, Miss Clark does believe that, before school age, deaf children should mix with hearing children.

> The one deaf child placed in a hearing nursery school or playgroup may be bewildered and appear to learn nothing. He may not be able, at five, to repeat a few over-learned words to order, but he may well be much more advanced linguistically than the deaf child who can. In the company of normal hearing children he may well have learned something of the purpose of language, its various uses and its relevance for living.
>
> (Clark, 1978)

3.11 In contrast, Darcy Dale, who runs the course for teachers of the deaf at the University of London Institute of Education, argues for the individual integration of deaf children in ordinary schools (Dale, 1978). He believes that residential special provision tears the children away from their home communities and special units in ordinary day schools preserve not only the stigma of belonging to a disabled group, 'the deaf', but the social isolation and unintelligible speech characteristic of special schools which rely on sign language. In fact, most teachers of the deaf use an approach called 'total communication' which combines manual and oral techniques and, with integration, there is no reason why hearing children should not also learn the signs.

Speech therapist working with a teenager with a hearing impairment.

3.12 In an article in *The Times Educational Supplement* (21 August 1981), Graeme Kent, head of a primary school in Lincolnshire, describes how the integration of deaf children into his school was facilitated by the hearing aid known as a 'phonic ear', a transistorized radio microphone system, which, though far from cheap, 'liberated our deaf children to a degree we had never dreamed possible'. In a school with classes of up to more than forty children,

> we are convinced that it is possible to integrate these handicapped children with advantage to all concerned. Obviously the deaf boys and girls are always going to need specialist attention, and the presence of the unit and its dedicated teacher is essential. However, the unit is only there to help, the deaf children are members of the school.

3.13 Integration at the school is not a community-based affair, however, because the catchment area for the deaf children is much wider than for the other pupils, and only children with this one disability are at the moment involved. So resources are still concentrated, albeit within the ordinary system. In the US, as you saw in Unit 10, the integration of deaf children is seen as just part of the 'national, state, and local force dedicated to stronger support for the rights of all children . . . The national challenge to provide, by 1980, comprehensive services for all children with exceptional needs is another moving force in the integration movement' (Yater, 1977).

3.14 Thus, in practice, the 'educational implications' of physical, mental or sensory disabilities may be for the curriculum or for school placement. Or there may not be any special educational implications. Confusion, and unnecessary segregation, may be the result of fears about a disability, little understood popularly in terms of biological accuracy, but familiar in terms of beliefs about wild behaviour and a disturbing, unpredictable lack of self control.

20

£262,500 record damages for anaesthetic error

By Aileen Ballantyne

A young woman teacher who is mentally handicapped and partly blind as a result of an operating theatre accident was awarded record damages of £262,500 at the High Court in London yesterday.

And at the High Court in Manchester, £200,000 damages was awarded to a 45-year-old man whose suicide attempt in hospital left him paralysed for life. Both awards were made against area health authorities.

Miss Elizabeth Shewan was aged 25 when she went into Westminster Hospital, London, for a routine operation. An "improvised" repair of the anaesthetic machine had gone unnoticed and she received anaesthetic instead of oxygen. Now aged 30, Elizabeth had "a shadowy and confused existence" her counsel, Mr Roy Beldam, QC, told Mr Justice Griffiths.

"The accident led to the waste of a young and promising life and caused heartbreak to her family," he said. She would need constant care for the rest of her life.

Mr John Shewan said he would use the money to give his daughter "some satisfaction from what is called life." She could do nothing for herself now except sleep and sit in a chair, but he hoped that by caring for her himself with the help of two or three nurses they would make "some impression."

"At the age of 57 I can only give my daughter about 10 years of my life—and I have to do the best I can for her in that time," he said. Mr Shewan hopes to set up a small semi-domestic residential home for her with the money.

"No one has won this case," he added. "What has been done is irreversible, and I have lost my daughter."

At present Elizabeth is being cared for in St Andrew's Hospital, Northampton, a private psychiatric hospital. Her parents, who have one other daughter, aged 16, live in Bearsted, near Maidstone in Kent.

Kensington and Chelsea and Westminster Area Health Authority, which admitted liability said it had brought proceedings against the makers of the anaesthetic equipment.

Elizabeth Shewan — pictured with her father John—who suffered brain damage in an operation which went wrong

The area administrator, Mr David Kenny, said after the hearing that the authority had already been asked by the Government to make cuts of £2 millions. "Anything extra we have to pay is obviously going to make things more difficult. We hope to be able to agree some method of handling this with the regional authority, North-west Thames."

Health authorities are not permitted to carry insurance against such claims, a spokesman said.

£269,000 damages for boy, 7

A seven-year-old boy locked for ever in the world of a one-year-old after a medical "calamity" was yesterday awarded damages of £269,698 in the High Court in London.

The damages, the second highest awarded in Britain in the High Court, went to James Croke for brain damage he suffered after a hospital blunder in 1973 when he was 21 months old.

A doctor had diagnosed "teething troubles" when James actually had croup.

Then, in Northwick Park Hospital, Harrow, Middlesex, when the child's throat was forcibly examined, he suffered a cardio-respiratory arrest which left him almost blind, paralysed in all limbs and mentally retarded, said Mr Justice Michael Davies.

Brain damage turned him from a "clever, bright little boy with a lovely personality to a shadow of the fine man he would have become," said the judge. His mental development was below that of a one-year-old.

Brent and Harrow Area Health Authority, against which the damages and costs were awarded, admitted full liability.

The judge praised the loving care given to James by his parents, 41-year-old former teacher Mrs Bridget Croke and her self-employed husband, James, a builder, aged 32, of Kingshill Drive, Kenton, Harrow. "It is quite impossible to speak too highly of them," he said.

Although James was by no means a "cabbage," and liked to be picked up and cuddled, he could not sit up and had sleeping and feeding difficulties.

It took an hour to get him up and dress him in the morning. His two great pleasures in life were listening to records and being bathed.

The award included £35,000 to the parents, for the "anguish and distress they must feel as daily they gaze on their son," for the mother's lost earnings as a teacher, for home help and other expenses.

In assessing James's damages the judge assumed that he would live to the age of 40, and awarded £130,000 for future care, an agreed £15,000 for a new bungalow, and £45,000 for James's future earnings loss.

He granted a 28-day stay of execution pending a possible appeal by the health authority on the amount of the award, the third large award against health authorities in a fortnight.

Mr and Mrs Croke have two other children, Helen, aged four, and Paul, two.

34

Epilepsy

3.15 Epilepsy is just such a disability (see the *Glossary* for a fairly detailed description). Children with a whole variety of epileptic disorders do have real learning difficulties, but these are often made worse by the rejection of teachers and by the drug treatment prescribed:

> [poor] seizure control still too often leads to increased dosages and polytherapy, with consequent toxicity and deterioration in overall performance. More education of teachers about possible implications of epilepsy and its treatment for school performance would help to detect and correct these problems at an earlier stage. Despite recommendations to this end in the Court Report (1973) and the Warnock Report (1978), such information is not readily available to parents and teachers except through the publications of the British Epilepsy Association . . . A diagnosis of epilepsy is compatible with the whole range of intellect and aptitude.
>
> (Craig, 1981)

3.16 Andrew Craig is the head of education and training for the British Epilepsy Association (BEA) and he deplores the kind of uninformative and derogatory psychological or school report which merely says of a child, 'known epileptic'. He presses for the education of more children with epileptic disorders to take place in ordinary schools alongside a publicity campaign to reduce the widespread hostility towards those with epilepsy: ' "Self-stigmatization" by families whose child's seizure disorder is relatively mild or infrequent is an ironic and preventable consequence of the fear of public disclosure and the price a family may pay for "passing" as normal.'

3.17 While endorsing many of the proposals contained in the Warnock Report (DES, 1978), the British Epilepsy Association's official comment contained this reservation about the term 'learning difficulties':

> Where epilepsy is concerned, problems encountered by the child in school may in fact stem from '*teaching* difficulties' which are dressed up as the alleged inability of staff in mainstream schools to cope with epilepsy . . . and can result in the exclusion of a child with epilepsy from the benefits of mainstream education for which he or she is otherwise quite suited intellectually.
>
> (BEA, 1979)

3.18 How does a child feel about having epilepsy, and what happens to her educatior ? Here is the story of a girl of 13, told by Dr Gregory Stones of the National Centre for Children with Epilepsy at Park Hospital in Oxford:

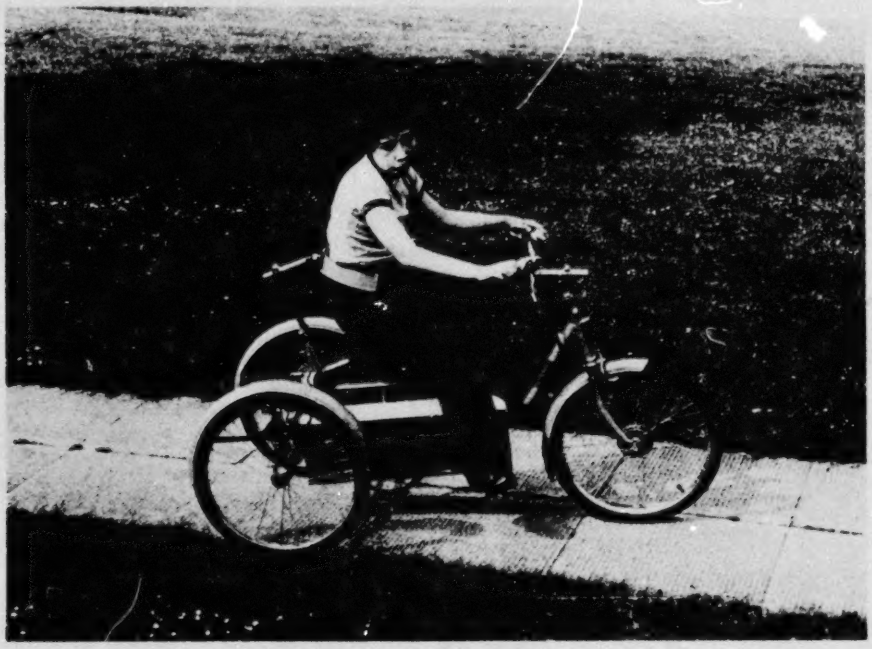
> Rebecca is 13 and an only child. At the age of nine she began to have seizures in which her right arm jerked repeatedly. These attacks have continued ever since, sometimes for up to several minutes during which time she is fully aware but unable to speak. At other times she has had generalised convulsions without known focal features. Recent EEGs have suggested independent local abnormalities in both hemispheres. In addition, generalised seizure discharge has been seen in the records associated with brief lapses of consciousness and eye flickering, revealing absence seizures which had previously been overlooked. Rebecca's seizures appear to be more frequent just before her monthly periods or when she is excited or upset.
>
> She has a facial rash and several small, pale areas on her body. These might be the signs of tuberose sclerosis although there is no clear family history of this condition. In other respects she is healthy and special tests have so far all been normal.
>
> In the past, even small amounts of anti-epileptic drugs have readily made her sick. For a period of time she was very drowsy and this was found to be due to phenytoin intoxication as shown by blood level measurements. Rebecca's teachers have often remarked on her slowness and tendency to daydream. These features could have been an effect of her drugs or subtle absence seizures.
>
> Psychological testing in hospital has shown her to be of average overall intelligence with no specific learning difficulties. Her reading skills are marginally impaired but her spelling and mathematical abilities are about three years below expectation for her age and overall intelligence.
>
> Rebecca is a very shy girl who obviously lacks confidence. She was teased a lot at school and now tends to avoid other children. She is clearly anxious about

herself and is frequently tearful. Her parents have additional domestic problems about which they will need advice.

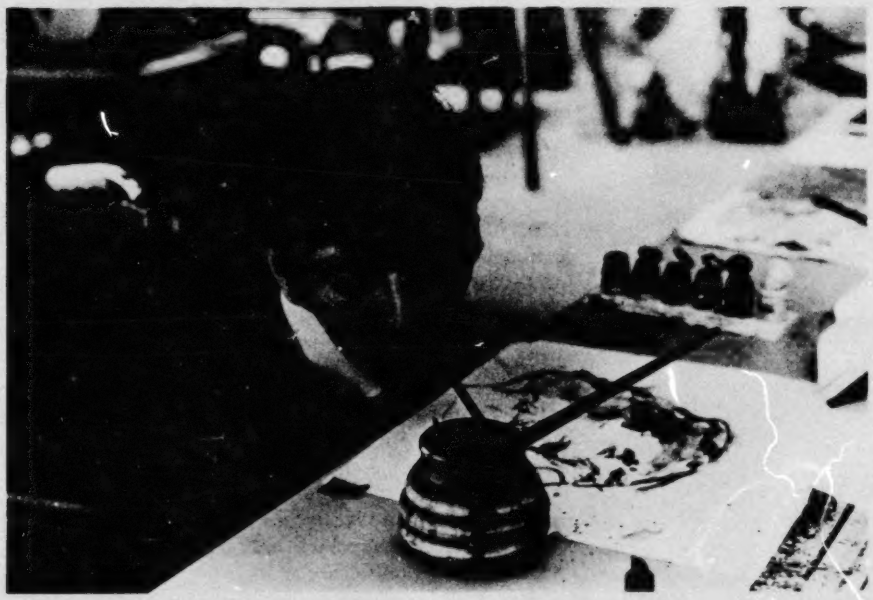
(Stones, 1979)

3.19 Dr Stones tells us of Rebecca's abnormal biology, but also that she is of average intelligence and has no specific learning difficulties. It seems as if her actual problems with school work have a lot to do with her own attitudes towards herself and with her experiences of the attitudes of those around her.

3.20 The main educational implications of physical impairment thus appear to be that it is hard for children with disabilities to belong to the heterogeneous groups to which others in everyday life belong, and that it is the organizational features of ordinary schools that particularly exclude many children who could well participate, but for the lack of a ramp, an extra pair of hands, a small class, or a peripatetic physiotherapist.



An adapted bike with back support and covered chain.



Mouth painting.

22

Support for classroom work.

4 *The syndromes syndrome*

4.1 In the previous section I described how children with demonstrable neurological damage face real problems in school because of their difficulties with speaking, moving about, concentrating, understanding visual-spatial concepts, and responding to instructions. But I also said that descriptions like 'epileptic' give no indication of the severity of the impairment nor of any consequent educational handicaps. Similarly, children with no known impairment but who experience great difficulties at school become labelled in this broad categorical fashion, their characteristic behaviours being grouped together as 'syndromes', the causes hinted at in medical-biological terms.

4.2 'Autistic', 'dyslexic' and 'hyperactive' children present problems which teachers find particularly hard to cope with or solve. Are they the result of actual neurological damage and, if so, how can you tell? Or are the labels, in the majority of cases, used as a negative judgement on the children who don't fit in at school? Can a medically diagnostic approach to social and educational problems be useful, except to validate the prescription of drugs and justify segregated education? Can any such 'diagnosis', in fact, be the objective, uniform conclusion implied by the *science* of medicine? When labels for difficult children are in the official repertoire, they are likely to be used, and so, if there are some children, autistic, dyslexic and hyperactive, who are minimally brain damaged, the number described as such will be far greater.

Autism

4.3 Some children seem to prefer a depopulated world of their own, not being able to comprehend or enjoy contact or communication with others, and their social dislocation can be permanently handicapping. From infancy, their unresponsiveness indicates some kind of serious disturbance, which consequently disrupts relationships with their mothers, family, peers, and so on. These children show little interest in smiling, in holding eye-contact, in being cuddled, or in feeding well, and they may either cry a great deal or hardly at all. It is not surprising, therefore, that the roots of this disturbing behaviour have been traced by some to the failure to establish satisfying relationships soon after birth:

> Tredgold and Soddy [in a text book on mental deficiency] have suggested that the key to causation lies in the infantile feeding satisfaction pattern of the child. Normally the first external experiences of the baby are related to this, and also his first emotional experiences. From this develops his first rudimentary consciousness of self and awareness of environmental objects, notably his mother. Thus his first primitive satisfaction, namely relief from hunger, becomes linked gradually with the associated pleasures of cuddling, caressing, watching his mother, etc., and as he gets older these latter pleasures become more important . . . Tredgold and Soddy suggest that it is when this development fails to take place for one reason or another that the autistic pattern starts . . . that the consequence of this failure is that the child remains, as it were, imprisoned in his own body, which he fails to identify as a separate entity.
>
> (Furneaux, 1981)

4.4 Leo Kanner, an American professor of child psychiatry, and coiner (in the 1940s) of the term 'early infantile autism', was inclined to believe in inherited personality traits rather than abnormal physiology, organic defects or emotional deprivation.

4.5 Later behaviour, however, suggests to some people that impairment to the parts of the brain responsible for integrating perceptual experiences and for controlling the tolerance of pain are involved. So-called 'autistic' children frequently have no speech or use words inappropriately, seeming either deaf or just uncomprehending. They can be fearful of everyday objects but not of lethal fires or traffic; they show a great resistance to changes in routine or their immediate environment, and display obsessive flapping, flicking, rocking and spinning. It has been argued that such children are over-aroused and therefore seek perceptual monotony, showing the same kind of distress as babies who are wakened at the wrong time. They can display abnormal sleeping patterns and abnormal patterns of electrical activity in the brain. So, small things may drive them either to frenzy or to trance-like inactivity. But there is great diversity among children labelled as 'autistic'. They do not form a homogeneous group and individual children need not share any common 'symptoms' with others so labelled.

Special educational referral

4.6 As Barbara Furneaux points out, 'at some stage of his development every normal child displays every item of behaviour' that characterizes the autistic child (1981). Which leaves it wide open to describe behaviour as 'autistic' if it is ritualistic, bizarre, isolating, repeated obsessively and displayed by children who should have outgrown it. Such an inclusive label, within which may be found as many individual variations as

there are children so called, not only functions to identify a set of disabilities, but could also be used for children whose behaviour is immature, unpredictable or anti-social, who thus are judged to have 'autistic tendencies'. The number of children involved is small: ten years ago there were 45 special schools and classes for the autistic in the country. There are a few special schools run by voluntary societies (the National Society for Autistic Children was founded in 1962) and a few LEA schools and classes, twenty seven in the London area. Children labelled 'autistic' are also often referred to schools for the ESN(S) although likelihood of appropriate teaching for the children or adequate support for the staff is small.

Educational implications

4.7 Two articles by Lawrence Bartak and Michael Rutter (1973) discuss various approaches to the education of autistic children, following a group of children for four years. Would it make any difference to your views about teaching methods, about integration or segregation, about school organization and about staffing ratios, if you believed autism to be the result of emotional disturbance or believed it to be an organic disorder specific to language and perception? Bartak and Rutter studied three units: one in which the approach was psychotherapeutic, with little teaching; one in which specific skills were taught in a highly structured setting; and one which resembled the permissive classroom of a typical primary school. They concluded that 'an autistic unit with large amounts of specific teaching in a well-controlled classroom situation is likely to bring the greatest benefits in terms of scholastic progress'. The main factor, however, was that special units have a higher staff–pupil ratio: 'Autistic children are most inclined to engage in stereotypic and disruptive behaviour when left to their own devices. Because autistic children persist for such short times in constructive activities when unsupervised, a high staff–child ratio as well as high staff activity is necessary'. Which is an argument as derivable from common sense as from medical or psychiatric wisdom. Also, factors such as staffing levels are not necessary features of any one size of school building. Moreover, so called 'autistic' children are beyond the pale of the behaviourist techniques so fashionable in special education at the moment because there are few things that they find rewarding.

Dyslexia

4.8 Like 'autism', 'dyslexia' is thought to involve impairment to perceptual, integrative and expressive processes, which here results in 'reading disorder', a specific learning disability. Writing and reading are peppered with reversals, rotations, additions, deletions, and substitutions. 'Developmental dyslexia' was first coined in 1968 by a research group led by the neurologist, Dr Macdonald Critchley, and defined as: 'A disorder manifested by difficulty in learning to read despite conventional instruction, adequate intelligence and socio-cultural opportunity . . . dependent upon fundamental cognitive disabilities which are frequently of constitutional origin' (DES, 1971, para. 4).

4.9 One writer has distinguished three possible types of relevant brain damage: first, that leading to obvious damage, such as spasticity; second, a more specific damage to a part of the foetal brain, resulting in impaired language abilities, speech or hearing; and third, damage caused by hereditary factors that could impair perceptual functions, such as the ability to read. In *Know Your Genes* (1980), Aubrey Milunsky cites a Swedish study of family histories which concluded that 'dyslexia was transmitted as a dominant disorder'. A genetic argument may be of comfort to parents and teachers because it minimizes their possible part in the development of the problem, but it will not hold out much hope of a cure.

4.10 Three official educational reports in the UK, however, have cast doubts on the existence of such a neurological disorder. First, the Plowden Report:

> Some of our witnesses have suggested the existence of a specific developmental dyslexia . . . a failure in reading which is thought to be due to neurological causes. There are so many possible reasons for poor reading, such as late maturation, ill-timed or poor teaching, sensory and speech defects, strephosymbolia (misperceptions of letters or numbers which usually correct themselves in time) and the emotional disturbances which may both cause, and result from,

retardation in reading, that it is difficult to be sure whether specific dyslexia exists as an independent factor.

(Central Advisory Council for Education, 1967).

Second, the Tizard Report:

> Many children who display features said to be characteristic of 'dyslexia' can in fact read well; others who read badly display few if any of the classical diagnostic signs.
>
> We take the view that . . . there is really a continuum spanning the whole range of reading abilities from those of the most fluent readers to those with the most severe difficulties . . . unless a 'specific developmental dyslexia' group could be positively and very precisely differentiated, there is a danger that attention would focus on the group assessed as 'dyslexic' to the disadvantage of those with perhaps equally severe difficulties but who happened not to be so assessed . . .
>
> We are highly sceptical of the view that a syndrome of 'developmental dyslexia' with a specific underlying cause and specific symptoms has been identified. Since the term 'dyslexia' has recently been used so very loosely and misleadingly . . . we think it would be better to adopt a more useful descriptive term, 'specific reading difficulties'.
>
> (DES, 1971)

Third, the Bullock Report:

> There is a small group of children who experience a difficulty in learning to read that cannot be accounted for by limited ability or by emotional or extraneous factors. The term 'dyslexic' is commonly applied to these children. We believe that this term serves little useful purpose other than to draw attention to the fact that the problems of these children can be chronic and severe. It is not susceptible to precise operational definition; nor does it indicate any clearly defined course of treatment. Most of the children, however, do find difficulties in auditory and visual discrimination and in associating visual symbols with the sounds they represent, and it has been suggested that these difficulties are caused by delayed maturation of the co-ordinating processes of the nervous system. A more helpful term to describe the situation of these children is 'specific reading retardation'.
>
> (DES, 1975)

4.11 Nevertheless, in 1972, a national British Dyslexia Association was formed by the Invalid Children's Aid Association out of 21 local groups, and there is also a Dyslexia Institute, a voluntary organization, which provides psychological assessment of specific reading, writing and spelling difficulties, specialist teaching, an advisory service, research and teacher training. Not all LEAs believe in dyslexia, however, and parents in Birmingham were taken to court because they withdrew their children for teaching at a special centre.

4.12 Groups seem to have been formed to keep dyslexic children *out* of special schools, rather than to rubber-stamp them for ease of referral for special education, and they do this by giving the label (still a necessary part of the campaign) positive connotations, so that attendance at the special class at a teachers' centre, for example, could be seen to be just like going off to music or elocution lessons, somehow associated with the problems that bright children have. This may be true, but it also underlines the fact that a supposedly neutral diagnostic label has inevitable social meanings as well.

4.13 While I was writing this, Susan Hampshire again brought dyslexia into the public eye by publishing a book telling her own story. Hers is one of success, but she still finds reading and spelling mysteriously and erratically difficult. In 1981 as well, Mrs Daphne Hamilton Fairley, a speech therapist and widow of the cancer expert killed by the IRA in 1975, opened a private school for 70 dyslexic children in London. The Dyslexia Institute assesses about 1500 children a year and provides classes for about 600 children and adults. Positive publicity and private enterprise, then, is lively in the early 1980s, and the director of studies at the Dyslexia Institute, Dr Harry Chasty, denies that dyslexia is a middle class invention to explain school failure. But it is also estimated that about 500,000 schoolchildren have severe reading and spelling difficulties. The Dyslexia Institute may be right to say that LEA remedial provision is inadequate, but it is hard to see how voluntary schemes can reach the majority of children with specific reading problems.

Hyperactivity

4.14 Very active children are frequently diagnosed as being 'hyperactive' and the use of the label is being increasingly criticized as a far too casual way of securing the sedation of classroom nuisances.

Reading Now read ' "Hyperactive" children' (Case study 9).

Comment The boys' behaviour and how their parents handle them are quite different and yet a diagnosis of 'hyperactive' was suggested for all three. Geoffrey seems to have been generally immature, but his family were willing to co-operate with professionals, even agreeing to the prescription of drugs for Geoffrey and to becoming involved in psychotherapy themselves. By the age of eight, medication, support at school and at the child psychiatric clinic were all removed and Geoffrey can now cope more calmly with life. Brian, on the other hand, is quite insecure and his tale is one of rejection, both by his parents, who were experiencing difficulties themselves, and by his school, who suspended him at five. At seven, Brian was referred to a residential special school for maladjusted children. Matthew was hyperactive, but only according to his parents, who were keen to have him referred to a special school. His parents seem to have concentrated their own problems in Matthew and were unable to accept that Matthew was in no need of special help. These brief accounts show that the role children play in their families are of prime importance to their behavioural, social and intellectual development, that categorical diagnoses mask a myriad of individual differences and that speculation about minimal brain damage would have been irrelevant to the options taken up (or refused).

4.15 Hyperactivity is popularized in hair-raising style. In an article in *Nursery World*, Dr Judith Haynes, a psychologist, discussed hyperactivity for a readership of nurses and mothers (some of us expectant at the time) in a clinical, detached way and, although she grants that it is 'a social and educational problem', her language is medical and biological and her tone occasionally patronizing (Haynes, 1980). Her most irresponsible tactic was to start a technically worded scare and follow it with reassurance, for example:

> Some hyperactive children may have a detectable impairment in their brain, but it is clear that the majority do not . . . 'Brain dysfunction' may be a more accurate term for these children than 'brain damage' since it refers to children with subtle neurological defects. However, many hyperactive children do not reveal even subtle defects of co-ordination, perception or language. Behavioural abnormality is the one constant feature of hyperactivity, but the causes are certainly various and not necessarily physical.
>
> (Haynes, 1980)

(I have discovered that this passage is taken almost word for word from Cantwell, 1975, p. 4. See below.) Dr Haynes goes on: 'Psychosurgery is the most drastic and irreversible technique for dealing with the adjustment problems. However, I feel that since at any stage hyperactivity may be a reversible condition in the child, on these grounds alone it can never be a recommended form of treatment.' If this leaves you reeling, here is some soothing ointment:

> The hyperactive child may also be suffering from far too little opportunity for really uninhibited physical exercise. Perhaps if hyperactivity really is on the increase it may well be due to increasing pressures of everyday life and the increasingly small space in which we have to live. For example, surely nothing brings peace and relaxation to a child more than a day happily and busily involved pottering about on a beach.
>
> If your child is 'hyperactive' do think of the external emotional and physical sources of strain on him and try to make more room for his own self to grow.
>
> (Haynes, 1980).

4.16 However, Dr Haynes does say, 'a hyperactive child may be reflecting tensions and unhappiness in his parents', and that a hyperactive child can 'become the scapegoat for tensions and problems which really belong to other members of the family'.

27

4.17 The authors of *Lead or Health*, the Conservation Society Pollution Working Party's critical response to the official government report *Lead and Health* (the Lawther Report, DHSS, 1980), admit that 'hyperactivity is . . . a condition which falls awkwardly between the social and medical sciences . . . some people see it as essentially a social, legal, and moral problem, and even . . . resent attempts to treat it by drugs as an attack on individuality and non-conformity'. But they support the medical view, arguing that

> hyperactivity is often found in children with cerebral palsy, temporal lobe epilepsy, and other mental defects . . . It may be seen in conjunction with symptoms of abnormal clumsiness and poor co-ordination, and specific educational difficulties, notably dyslexia and dysgraphia. For this reason, hyperactivity has come to be included among the symptoms of 'minimal brain dysfunction'. (Some people appear to dislike this approach because they feel it places a stigma on the child.)
>
> (Conservation Society, 1980)

4.18 A psychiatric view is given by Dennis Cantwell (1975) and Sandberg *et al.* (1978). Cantwell outlines

> a symptom pattern of hyperactivity, impulsivity, distractibility and excitability. Aggresive and antisocial behaviour, specific learning problems and emotional lability are often considered part of the syndrome . . . the term 'hyperactive child syndrome' will be used to denote a behavioural syndrome only, with no implications as to etiology . . . However, the hyperactive child syndrome is also known to be common in children with low IQ . . . with frank brain damage . . . and with epilepsy . . . clinical studies of the parents of children with the hyperactive child syndrome indicate that a significant percentage were themselves hyperactive as children and are psychiatrically disturbed as adults.
>
> (Cantwell, 1975)

Although Cantwell remains neutral about causes, he cites evidence for brain abnormality, physiological arousal abnormality and genetic factors. Hyperactivity is 'one of the more important psychiatric disorders of childhood'; 'child psychiatry is a branch of medicine and a medical model is entirely appropriate for the investigation of the psychiatric disorders of childhood'.

4.19 Sandberg *et al.* discuss the huge difference in diagnostic practices, though not necessarily in prevalence of the 'symptoms', between the US (Cantwell's empire is in Los Angeles) and Britain. In the US, about four to ten per cent of school age children are diagnosed as having the 'hyperkinetic syndrome' and fifty per cent of these are referred to a psychiatrist; in Britain only about one in a thousand is thus diagnosed. Here, the term 'conduct disorder' is more common (derived from Rutter's classification of child psychiatric problems, 1965) and does not carry with it the implications of neurological damage. British psychiatrists tend to reserve the term 'hyperactive' for a very small group of retarded, neurologically abnormal, impulsive children, many of whom suffered perinatal complications. Despite the widespread discussion of brain damage in connection with hyperactivity, most authors keep reminding us that very few hyperactive children have any abnormality in the brain and that few of those who do are hyperactive. 'There is no particularly close connection between overactivity and neurological abnormality' (Sandberg *et al.*, 1978).

4.20 So why classify children as 'hyperactive'? This is the question asked by Peter Schrag and Diane Divoky in *The Myth of the Hyperactive Child* (1981). Their answer: 'despair with the proposals for social reform of the sixties, and a mushrooming faith . . . in the possibilities of screening, diagnosing and treating individuals . . . signalled the beginning of what would, in effect, constitute a new era in the social and psychological control of children in America'. And medical intervention is faster than improving social or economic circumstances. 'There was the view of the child as patient coupled with the supreme confidence in the ability of 'trained professionals' to write accurate 'prescriptions' and offer effective remedies'. Schrag and Divoky describe this as a 'demonology' of deviance, which permits 'psychosurgery on seven-year-old 'hyperactive' children to make them docile' and which is the result of 'the dramatic growth of an ideology which sees almost all nonconformity as sickness and which, in the name of prevention, imposes increasingly narrow limits on what it will accept as tolerable behaviour'. New labels 'converted what had been the observations of admittedly fallible human beings ('the kid can't sit still') into disease ('hyperkinesis').'

4.21 The existence of genuine disabilities, such as hearing and speech problems, brain damage and mental retardation 'furnished a convenient and plausible rationale for the creation of others which were essentially social, not medical, in nature'. Treatment became a matter of 'institutional convenience'. Schrag and Divoky argue that hyperactivity in the US is a 'synthetic disease' invented to perpetuate the smooth running of the status quo. When a school could neither control nor get rid of its 'hyperactive' children, their parents would be shown the way to obtain a prescription for tranquilisers. The implication is that the hyperactive child is a 'pre-delinquent', a virus in a sterilized world.

4.22 They argue that the problem does not lie within the child. It is the problem of a society which fears so many of its novitiates. In his article 'On the medicalization of deviance and social control', Peter Conrad (1980) also argues that deviance has come to be described as 'sickness' and that a medical model of diagnosis, treatment and cure is social control masquerading as the restoration of health. Schrag and Divoky and Conrad discuss the uses and abuses of 'hyperactivity', which is a negative social judgement, a condition from which a sufferer would obviously want to recover. Conrad also provides us with a possible solution to the problem of whether or not any 'hyperactive' children have some kind of brain damage, given that we cannot tell.

4.23 The presence of actual organic damage is irrelevant. What matters is that a diagnosis of 'hyperactivity' is regarded as valid, that it is a condition in which brain damage, though admittedly very unusual, is nevertheless possible. A prerequisite for medicalization 'is the existence of some ambiguous organic data as to the source of the problem'. This is vital, for it keeps hyperactivity within the scope of the doctors and thus on the list of diseases for which drugs may legitimately be prescribed: 'Treatments, such as behaviour modification and medication, rather than punishments are more acceptable in our society . . . The major source of treatment expertise is the medical profession' (Conrad, 1980). Medical 'forms of control are, if nothing else, generally more efficient than other forms of control and may be implemented in the name of humanitarian progress'.

Drugs

4.24 Some disabled children need drugs to combat pain, infection, or convulsions, and so there is a legitimate place for their use among the groups of children found in special education. However, the availability of tranquillizing drugs, the increasing panic caused by children referred as 'maladjusted', 'disruptive' and 'hyperactive' and the continuing involvement of doctors in special education have made it easy to extend the practice of prescribing to control large numbers of children with behavioural and emotional problems. Dosing children often takes place, not in huge, barren, grossly understaffed residential institutions, but in small, newly-set-up, well-equipped and staffed special units, with the concurrence of family and educators. Drug the children if you're afraid of what they might do, might become, or if they disturb you by their own unhappiness.

4.25 Drugs, of course, are not punitive, but 'therapeutic'. Corporal punishment and social isolation are still used in segregated provisions (see the *Where* article, 'Beating children in care', June 1981, and the report of the punishment room at Broughton Tower residential school for maladjusted children in *The Guardian*, 1 June 1981), but these measures receive more public criticism, except when drug abuse is revealed in safely remote psychiatric hospitals. When authors based at the Institute of Psychiatry write, 'Children with a wide range of behavioural and learning problems respond well to stimulants and there is no evidence at the moment for a specific drug response' (Sandberg *et al.*, 1978), they give the impression that prescribing is both a genuine and an appropriate response to need. Moreover, while we may not want to be beaten or locked up (i.e. punished), we voluntarily take drugs and so are unlikely to object on principle. Also, drugging is a relatively cheap form of control. One writer believes that such objections would be detrimental to the child:

> The advantages of having appropriate medication readily available for the treatment of behavioural disorders must be weighed against the dangers or disadvantages of rigid drug restrictions and the possible withholding of treatment from a child who may clearly benefit from drugs. Provided the medicine is of proven efficacy . . . a child should not be denied a therapy that will control his hyperactivity, increase his attention span, and permit him to achieve to the

> level of his potential. It is the consensus among physicians that there is a place for central nervous system stimulants in the treatment of hyperkinetic disorders in children.
>
> (Millichip, neurologist and paediatrician, 1973)

4.26 Tranquillizing children is far more widespread in the US than it is here, where the majority of about a million 'hyperactive' children receive drug treatment, keeping the coffers of the pharmaceutical industry full, the academic researchers busy fulfilling their obligations to evaluate drug therapy, and the doctors influential in special education. In his preface to the British edition of *The Myth of the Hyperactive Child*, Stephen Box contrasts the medical view: 'only by developing a national sensitivity to child psychiatric and learning problems, instituting early identification and prevention programmes, and providing special educational and medical resources can this epidemic be managed and the more serious forms of adult anti-social behaviour averted', with the sociological view:

> hyperactivity is *not* a genuine disorder or disturbance but a label which provides comfort to parents, teachers and maybe other school pupils. The growth of hyperactivity and other child behaviour disorders is not a medical epidemic, but a moral panic amongst parents, teachers and educational administrators, whipped up by increased school indiscipline and the pharmaceutical industry.
>
> (Box, 1981)

4.27 Professor Martin Herbert argues that while drugs, such as the stimulant methylphenidate, do reduce overactivity, impulsivity and distractibility, their effects are only short-term, 'they have little impact on [children's] long-term social, academic or psychological adjustment', and that medication given over several years runs the 'psychological risk' that change will be attributed to the pills and not the child: 'This constitutes a dangerous erosion of responsibility and self direction' (Herbert, 1979). Behaviour modification is the approach he favours, to try to 'break through the vicious circle of out-of-control behaviour which makes hyperactive children so unrewarding to parents and teachers, who in turn become aversive stimuli to them'. Herbert's solution, however, still includes a professional controlling of undesirable children.

4.28 Drugs do not necessarily improve a child's academic or creative performance, and they can make children more irritable, overactive or clumsy. One study found that 127 mentally retarded people with epilepsy were suffering further damage from the toxic effects of phenytoin, the drug given to control their convulsions. But drugs make children more manageable, more willing to carry out routine tasks in school, 'which throws doubt on the sincerity of those who administer them, or reveals the naivety with which medical solutions to non-medical problems are embraced' (Box, 1981). Drugs are plentiful: the sedatives include Phenergan, Mogadon, Valium, Librium, Stelazine, Largactil, Mellevil, Menlactil, Serenace, Ritalin, Ronyl, and Dexedine. The pharmaceutical companies push their wares at the doctors 'as being useful for "hyperkinetic behaviour" (Ospolot), "to control hyperkinetic states" (Largactil) to control "hyperactivity and aggression" amongst children (Tofranil), and "of some benefit to the treatment of hyperkinetic children" (Benadyl)' (Box, 1981).

4.29 Another way of controlling 'hyperactivity' by means of a physical treatment has been explored by the Hyperactive Children's Support Group, founded in 1977 by a parent. This group believes that there is a connection between overactivity and certain food allergies—it is therefore a biological condition basically—and consequently diet is important. Dr Ben Feingold, of the San Francisco Medical Centre, has compiled a diet which reduces the proportion of food containing additives, such as artificial colouring and flavouring and salicylates (which prevent food going bad), which could be related to the problems of lead's presence in food via soil or tinned cans. In the US, an Interagency Collaborative Committee on Hyperkinesis has been trying to co-ordinate the experimental work testing Dr Feingold's hypothesis, which has proved very difficult, as most studies are not comparable. One study reported that hyperactivity could be produced by natural products like milk, wheat, egg, cocoa, corn and sugar. Holborow *et al.* (1981) concluded that 'the behaviour problems most likely to show improvement were distractibility, [short] attention span, fiddling and demands for attention . . . children who were reported to be taking a great deal of additive were found to rate significantly higher in behavioural problems compared with children receiving little additive.' Parents, although

often very hostile to the use of drugs, thus appear to support the idea that there is a biological basis for the behaviour of their 'hyperactive' children which they believe can be caused by lead pollution and perhaps ameliorated by a low-additive diet. Unmanageable behaviour can be intolerable for families, schools, or societies, and at the moment drugs and segregation, both 'prescribed' for the children only, are the most common forms of control.

Lead and hyperactivity

4.30 Lead is a poison and will affect the human central nervous system according to the quantities absorbed. Children are particularly vulnerable, as their nervous systems are still developing and they absorb lead more quickly than adults but retain it longer. Disturbances of behaviour and impairment of ability will occur before there are any obvious signs of illness. Lead can be breathed in the air, eaten in food, chewed from paintwork and swallowed in water. Among the early signs are irritability, colic, loss of appetite, apathy, anaemia, distractibility, lack of persistence, clumsiness, over-activity, and aggression. These can occur at blood lead levels of five mg/dl. Clinical symptoms of lead poisoning, which can occur at a blood lead level of about 40 mg/dl, are: convulsions, persistent vomiting, coma, ataxia, anorexia, excessive apathy. To bring attention to the fact that sub-clinical levels of lead can be seriously damaging to a child, socially and educationally, hyperactivity has been publicized as one of the indications of lead poisoning in order to put pressure on public authorities to reduce lead pollution, especially in the air (from petrol exhaust fumes) and in water (coming through old lead piping). This commits the lobby groups, such as the Hyperactive Children's Support Group (founded in 1977) or CALIP (the Campaign Against Lead in Petrol, founded in 1973), to believing in an organic basis for hyperactivity.

4.31 The Conservation Society's report mentioned in paragraph 4.17 seeks to establish that lead has serious effects before there are any perceptible symptoms, in terms of permanent changes in brain chemistry and structure. To do this they have to cite animal studies and then argue for a human parallel, as the only relevant parts of a child's body that can ethically be investigated for the toxic effects of lead are blood, hair and shed milk teeth. Rats who had been injected with doses of lead to give them a blood level of about 36 micrograms of lead per 100 millilitres of blood (which is comparable to human groups) grew normally and showed no clinical signs of poisoning (vomiting, anorexia, excessive lethargy, convulsions), but they displayed a whole range of behaviour that characterizes children called 'hyperactive', including increased motor activity, aggression and impaired co-ordination. The authors summarize this pattern as the inability to adapt to a changed environment.

Reading Now read 'The effects of lead pollution on children's development' (Reading 1.4), which contains extracts from both the Lawther Report (*Lead and Health*) and the Conservation Society Report (*Lead or Health*).

Comment The main dispute between the two reports concerns the evidence in favour of the existence of damage caused by comparatively small amounts of lead in the body. Neither deny that lead is toxic in sufficient quantities, which Lawther gives as 80 mg/dl and the Conservation Society as 40 mg/dl. The Lawther Report finds the current literature (excluding the animal studies) equivocal or methodologically unsound, and concludes that 'there is no convincing evidence of deleterious effects [on children] at blood lead concentrations below about 35 mg/dl'. The evidence from tooth lead levels might be more persuasive, but it is not comparable to the work that takes blood lead levels as the measure. The Conservation Society argues that disturbances can be seen at blood lead levels as low as five mg/dl, and cites studies of rats and of New York and Birmingham children. The authors justify their reliance on animal studies by arguing that neurochemical and social factors interact and therefore imply one another . . . They accuse the Lawther Committee of 'unwarranted complacency' and conclude that 'most UK children . . . are now suffering an epidemic, even a pandemic, of low-grade lead intoxication for which the addition of lead to petrol is largely, though not wholly, to blame'.

4.32 In this section I have presented a variety of views about what hyperactivity is, if it exists at all as a genuine distinct behavioural disturbance, what its origins are thought to be and what value these different characterizations have, and for whom. What are the biological implications of educational problems? Does biology intrude unjustifiably into the lives of children who have difficulties in school, diverting attention from problematic social interactions to individual children, or does a description of a whole range of actual and potential symptoms help towards understanding their problems?

4.33 Most children who experience difficulties in school would benefit from more adult attention and more help tailored to their individual problems, without shunting them out of sight socially. But when faced with children called 'autistic', 'dyslexic' and 'hyperactive', teachers of large classes in ordinary schools are not in a position to begin to try and do this. Understanding the children's problems in terms of syndromes which have a basis in organic damage or inherited personality characteristics may seem to make sense of a vague but all-embracing label and suggest some concrete course of action. This action, however, like that in a Greek tragedy, usually takes place off stage, outside the classroom, with the removal of the offender to a psychologist, psychiatrist or doctor.

5 *Medicine and education*

5.1 In this section I shall look at the involvement of the medical profession in the education system. On the one hand there are the beneficial contributions made by doctors to the welfare of school children; on the other hand there is their continuing influence over educational assessments, referral to special provisions and educational policy-making.

5.2 Advances in preventive medicine at the turn of the century and the simultaneous expansion of the state education system gave doctors the right and the opportunity to become involved with children via the schools, where, without doubt, their services were badly needed. The school medical service was set up in 1907, 41 years before the National Health Service, and school medical officers continued until the reorganization of the NHS in 1973 redeployed them in the new community-based health services.

5.3 However, from 1890, when doctors were first appointed to local school boards, to 1975, doctors had the final say in the selection of children for special education. LEA medical departments were also responsible for child guidance services, which developed during the late 1920s. And it was a doctor, Alfred Eichholz, appointed by the Education Department in 1898 to oversee physical training in schools, who became the first Inspector of Special Schools for the blind, deaf, defective and epileptic in 1903. In 1907 he joined the new Medical Branch, and in 1920 the inspection of special schools by Board of Education Medical Officers was officially confirmed. The response to protests that doctors were unqualified to inspect schools for the blind, for example, where medical requirements were minimal, was the appointment of an educational psychologist to the Medical Branch in 1931. In 1934, however, educational inspection of day schools for physically and mentally defective children became once more the responsibility of the district medical inspectors.

5.4 The first head of the School Medical Service was Dr George Newman. In a lecture he gave in 1930, he said:

> The doctor has joined in the national movement of collective humanism in behalf of the expansion and application of science to the betterment of man's estate. His sporadic and intermittent contribution has slowly become an organised national service . . . The purpose of Preventive Medicine is thus to improve environment, to develop innate capacity, to avoid disharmony in its early stages, in order to escape its later results in the body, and to prolong and enlarge man's day . . .

> The school medical service has proved itself a branch of Preventive Medicine by giving a new emphasis to the importance of the *beginnings* of disease; by reducing the results and disabling effects of disease in childhood; by providing physical care and training in the age period between infancy and adolescence, and so laying the foundation for health in adult life; and by establishing the fact that the health of the child is the foundation of the national health.
>
> The cooperation of medicine with the State has enabled us . . . to stamp out some of the chief enemies of health and life . . . It is an amazing story. By the practice of immunity and by improved nutrition the physical powers of resistance of large portions of the population have been fortified . . . It has all come to us so simply, steadily and silently that the younger generation accept it all as a matter of course and seem unaware that it represents a progress greater than any other in the whole range and history of English Medicine.
>
> (Newman, 1931)

5.5 Thus the medical knowledge and the professional outlook of doctors concerned with public health had their impact via the education system. Unit 7 looked at the legacy of early twentieth-century medical involvement and Units 8 and 9 took up the story of the battle for administrative control between school medical officers and educational psychologists.

5.6 Many disabled children rely on medical practices to maintain their level of general health and their continued participation in school life. For their disabilities, the medical approach of diagnosis and treatment is obviously appropriate. The kinds of preventive and corrective practices that involve doctors with disabled children include: courses of drugs, orthopaedic surgery, the provision of prosthetic aids, aids for personal hygiene, arranging for controlled diets and adequate physiotherapy; all of which also bring the doctor into a working relationship with the children's families and with other professionals. But the length of time many disabled children spend in hospital, or at home in bed, can reinforce their image of themselves as patients and may involve their doctors in a consideration of their educational programme. Community-based child health specialists are involved in screening for the early detection of disabilities, and, once these are detected, they visit children in the variety of local authority special provision to which the children are referred. How far they work together with non-health professionals is a matter for individual doctors to decide, but in at least one London borough, psychologists see many of the under fives.

5.7 Pain, anxiety, aggression—these are all concepts with physiological as well as social meanings, and educators may sensibly confer with doctors, whose advice will probably carry a great deal of weight. So much so that non-educational professionals may become ubiquitously influential. There is, for example, Michael Rutter, a professor of child psychiatry: teachers use his behaviour rating scale, educational psychologists use his classification of child psychiatric disorders when completing special education referral forms, and his definition of 'specific reading retardation' has been taken up by official DES committees as a more useful concept than dyslexia.

The limits of medical control

5.8 The doctors who argued that they should control the selection of children for special schools and the inspecting of these schools for the Board of Education had quite valid criticisms of the ordinary elementary schools. They believed that it was for the members of the medical profession to reform school architecture and hygiene and introduce PE, free milk and meals and adequate rest periods, thus organizing the timetable and curriculum as well as dealing with infectious diseases and physical disability.

5.9 But this sort of control can place doctors in a position where they became accountable only to fellow professionals of a higher rank, even when their own actions are a clear cause of serious disability. Unwillingness to take responsibility (for the administration of the wrong drug, for example) in cases of medically-induced disability is all too often reported. Two examples which were reported recently in national newspapers are shown overleaf. In each one it took five years to establish that the health authorities were responsible, and the damages awarded to James Croke have just been reduced, though not by as much as Lord Denning proposed.

Damages to boy crippled in hospital are reduced

Lord Denning, Master of the Rolls, was at odds with two other appeal judges yesterday over damages awarded for the pain and suffering of a baby injured during hospital treatment.

James Croke, now aged nine, of Pinner, Middlesex, was awarded total damages of £270,000 by a High Court judge in 1979.

Brent and Harrow Area Health Authority had admitted liability but argued that the damages were too high.

James is blind and paralysed in all four limbs. He cannot stand or talk. He is dependent on his mother for everything — feeding, washing, changing and dressing.

The accident happened when James was 21 months old when he became feverish with croup symptoms and was taken to Northwick Park Hospital Harrow. There something went wrong with the treatment. While doctors were examining his throat he could not get his breath and his heart stopped. He was put into intensive care and brought back to life, but the cardiac arrest had damaged his brain beyond repair.

The total damages award included £35,000 for pain and suffering. Lord Denning said that the award should be £25,000. Money was no solace at all when an injured person was not aware of his loss, he said.

But two other judges felt that the figure should stand. Lord Justice Shaw remarked: "It is in these days no more than the price of the more expensive sort of motor car, which is a standard amenity of most popular entertainers."

The baby boy's life was made barren when it had hardly begun, he said. He had no opportunity of enjoying any significant part of his life.

"Not the innocent joys of childhood for him, or the awkward pleasures of growing up, of adolescence, or of young manhood or of achievement." Lord Justice Griffiths agreed.

The figure was upheld but the total award was reduced by £37,000 because the judges felt that figures concerning future loss of earnings and nursing care were too high.

Lord Denning felt that a £45,000 element in the award to James for future loss of earnings should be cancelled. He said that if a baby of two years was deprived of all brain power so that it could do nothing and earn nothing it had no claim for damages for loss of earnings.

But the other two judges ruled that the figure should not be cancelled but reduced to £25,000, because James was not expected to live beyond 40.

Uses and abuses of a medical model

5.10 The main attractions of viewing disability wholly in medical terms are the implied hope of a cure and the removal of responsibility from the relatives and the community of the disabled person. The language of disease is familiar and concrete compared to that used to discuss attitudes and prejudice, and physical imagery has a direct force:

> There is always a danger of over-optimism when the first episode for the better occurs. To take such an episode as an indication for stopping or modifying a treatment programme is analogous to stopping a course of antibiotics half-way through. The body has not developed the inner resources to fight off a recurrent infection which expresses itself in a more violent form that is more difficult to treat.
>
> (Letter from an EP to a primary school head, 1974)

5.11 However, medical classifications can also justify buck-passing by other professionals:

> Medical classifications, such as 'minimal brain dysfunction', have provided a seemingly sophisticated and respectable excuse for both non-teaching and poor teaching. The teacher who is told that Mark has MBD may very understandably respond with some version of, 'No wonder I haven't been able to teach him', and quit trying. He has suddenly become something other than an ordinary child who needs more and better teaching than other children. He is now someone else's responsibility.
>
> (Bateman, 1974).

5.12 Medical ideas are very powerful in educational circles:

> The notion of handicap and its physical and biological connotations that emerged as a dominant concept in the rationale of special education made it possible to conceive of those children with special needs as a relatively fixed group of individual *'bodies'* . . . Educational difficulties were therefore *attached* to a separate group of children objectively different from the rest, as if they were physically handicapped.
> (Quicke, 1980)

We saw in the case study, 'Hyperactive children', how persistent Matthew's parents were about getting him 'diagnosed'. One educational psychologist argues that the use of medical models in connection with problem behaviour deceives us into thinking that 'maladjustment is an abnormality', rather than a reasonable response to a hostile environment; 'when we describe behaviour as "maladjusted" we are making a judgement about situations'; 'If we cannot have diseases, we can have disorders; and if the disorder is not precisely located somewhere within the child, at least he somehow wears it round him like an aura' (Roe, 1978).

5.13 Physical imagery locates disability within the individual, so that it becomes possible to view delinquency in biological terms, as the manifestation of innate subnormality or abnormality, a kind of disease which, as I have discussed above, may therefore be legitimately controlled by drugs.

> There is . . . a situation to be exploited by those who view conduct disorders and hyperactivity as having a biological cause. This would of course shift the 'guilt' for this large problem population from the teachers, or parents, or educational authorities, or the general environment, onto the children themselves. Biological situations, such as drug therapy, are also less costly per unit than changing the environment is, and provide a profit for corporations who manufacture [drugs]. At a time of economic crisis, both these factors seem to be important.
> (Box, 1981)

Those who view social and educational problems in biological, 'constitutional', terms are by no means always the medical practitioners themselves, but more often other professionals, psychologists or teachers, whose own status as scientific experts is thereby enhanced.

5.14 Dennis Cantwell argues that such a model does not entail anything about actual disease, but serves to clarify one's thinking without dehumanizing the person concerned:

> Every patient is a unique human being, and this uniqueness must be taken into account in any doctor-patient relationship. This is part of the art of medicine. Nevertheless, excess emphasis on the unique aspects of each patient and lack of recognition of the common factors shared by patients who present with a particular disorder will impede scientific study; 'a diagnosis . . . does not result in applying a label to a child'; 'the effective use of knowledge about a child's psychiatric disorder to relieve the suffering to the child and his family . . . is humanitarian in the highest sense of the word'.
> (Cantwell, 1975)

This is a credo that precludes any examination of the professionals' vested interests, or their preservation of power and inaccessibility by means of technical jargon and confidential records, and it also prevents them developing sensitivity to the great variability between people with the same impairment. Illich, on the other hand, argues that medical diagnosis results in a stigmatizing label:

> When a veterinarian diagnoses a cow's distemper, it doesn't usually affect the patient's behaviour. When a doctor diagnoses a human being, it does . . . The medical label may protect the patient from punishment only to submit him to interminable instruction, treatment, and discrimination, which are inflicted on him for his professionally presumed benefit.
> (Illich, 1977).

5.15 The link between sickness and handicap remains unbroken, and a recent example is the book *More than Sympathy: the everyday needs of sick and handicapped children and their families* (1981). The author, Richard Lansdown, is principal psychologist at the Hospital for Sick Children, Great Ormond Street, London. Mental handicap is treated in

a short chapter alongside others on cerebral palsy, diabetes, autism and visual loss. The chapters follow a common pattern with brief sections on definition, frequency, causes, psychological factors, treatment, management, education, the family, and so on, and the book is designed for people training to work with 'sick and handicapped children and their families, with particular reference to those concerned with psychological rather than medical problems' (Lansdown, 1981). The book is designed as a handbook of professional knowledge, and some of its information, such as the addresses of associations, is very useful. But there are many important issues about which the author is deliberately neutral, and which are therefore given a misleadingly small space: In the chapter on mental handicap, Richard Lansdown writes:

> The most commonly used measurement technique in this field is the intelligence test . . . The use of the concept of 'mental age' is, in my opinion, of uncertain value . . . Further criticisms involve the possibility that both the place of testing and the personality of the tester can affect scores. I do not go along with the argument that all intelligence tests should be abolished but I do think there is much support for criticisms that have been made.
>
> (Lansdown, 1981)

About special schools, he says:

> Anyone reading the last few paragraphs may think that I am carrying on a campaign for special schools . . . On the whole, if I am to declare a preference, I think special schools for the subnormal do well and provide much. But I have known bad schools, I have known children score consistently low on intelligence tests and yet hold their own in ordinary schools, I have known children transfer back from a special school to a comprehensive in the teeth of opposition from the special school head, and make a success of it. One lesson I have learned is never to make a hasty judgement.
>
> (Lansdown, 1981)

Non-medical, non-educational professionals seem to be the master-welders when it comes to perpetuating a medical model of handicap for use in schools.

Genetic counselling

5.16 Doctors can make a valuable contribution to those who are disabled or who have disabled children, however, through their work on genetic disorders and preventive genetic counselling. Genetic counselling has progressed with the increase in both reliable information on which to base advice and the availability of consultant geneticists. The first clinic was opened at the Hospital for Sick Children, Great Ormond Street (GOS), London, in 1946 and there is now a national network of them, with one in each hospital region and university medical school. Cedric Carter, until recently the director of the GOS clinic, summarized the objectives of genetic counselling as:

> To give information to parents and their relatives on the risks to future children, this information to include both the risk of disease and the prognosis for an affected child.
>
> To alert the medical profession to special risks to an as yet unborn child, thus facilitating early diagnosis and treatment.
>
> To prevent an increase in the birth frequency of genetically and part-genetically determined disease following the introduction of effective new treatments, and in the long term to reduce the birth frequency of such diseases well below the level normally maintained by the balance of mutation and selection.
>
> (Carter, 1971)

5.17 This last has been described by another consultant geneticist in the following way: 'Of less value at present, but with great promise for the future, is that medical genetics may also help us to outwit our inheritance' (Clarke, 1977). People with a known history of genetic disease in their family come to ask about the risk to their future children; parents who have had one unexpectedly disabled child want to know if the condition is genetic and, if so, the possible risks to siblings and grandchildren; those affected by genetic diseases may come to ask about the chances of having healthy children themselves. Parents of a Down's Syndrome adolescent girl may be worried about the possibility of

her becoming pregnant and ask for her to be sterilized. Demands for sterilization are not uncommon, but are frequently based on an ignorance of the low fertility of, for example, people with Down's Syndrome, and an alternative precaution would usually be sought. A pregnant woman may wait until it is too late to have an abortion, having perhaps been anxious for five months or so, to come and ask if the mental retardation and epilepsy of her brother could be passed on to her child. A young girl, perhaps about to become engaged, and who has a cousin who is deteriorating rapidly as a result of Duchenne's muscular dystrophy, may come to ask about the likelihood of being a carrier. But there are many parents who do not receive counselling and do have more than one child affected by inherited disease. They may not realize that a family or once-off disorder is in fact hereditary, or their doctor may not have been able to diagnose it. Sometimes, of course, information about family disease is deliberately kept secret. Nearly all referrals to genetic counselling clinics come via GPs (although they are usually initiated by the 'patient'), or community health physicians. One community specialist in child health who has long been closely involved with special education regards the automatic referral of families at risk of genetic disorders as a specific and valuable contribution of the community health services to the prevention of disability in children and strain in the parents. The present consultant clinical geneticist at GOS has noticed that 'the rare genetically determined disorders and congenital malformations are seen more frequently than those patients with epilepsy, schizophrenia, diabetes or any of the common disorders with less obvious genetic implications'. Many families seen 'expressed fears about the inheritance of epilepsy, and yet few people are counselled'; 'it is estimated that 85 per cent of those who run risks greater than one per cent from individual disease get no counselling at all. This takes no account of those with risks lower than one per cent who need reassurance' (Baraitser, 1980). Dr Baraitser argues that individual counselling by physicians can tackle the emotional and material problems faced by families with genetic disease and is preferable to a multi-disciplinary approach involving social workers. At GOS, however, there is now a case worker attached to the unit who is responsible for follow-up work with families. She is not on the establishment but paid for by the Muscular Dystrophy Group.

5.18 The evidence from a 1971 follow-up study of those who had attended the GOS clinic between 1952 and 1964 showed that two-thirds of the high-risk couples did not have any more planned children with a permanent disability. Counselling, then, reduces the population of children with potential special educational needs. These children themselves are now being counselled in some areas. Since 1973, Dr Mary Vowles, genetic counsellor in the Department of Paediatrics at the Royal Devon and Exeter Hospital has counselled nearly three hundred school-leavers with physical disabilities, visual handicap and hearing loss, and has given them an idea of their chances of having an affected child.

5.19 Counselling provided an opportunity for those whose handicap was not genetic (e.g. the result of infectious disease such as rubella or meningitis) to be reassured, and for pre-marital advice to be given in a setting (the young person's school) that was supportive for those who were upset by the risks.

5.20 The limitations of genetic counselling are that some conditions cannot be established satisfactorily by clinical tests, that the tests are not infallible, and that advice about likelihoods and probabilities may be interpreted as certainties. There is also a danger that the information and advice may be given in a more authoritarian way than is intended, so that the client may be put off—further appointments may be offered, but not taken up. On the clients' side, their motivation for tracing specific problems back to a defective gene may be the desire to discover natural causes for such things as dyslexia, thereby making the disability less personal. Some are really asking for advice about coping with disability, although their questions are ostensibly about something else, e.g. a teenager's fertility. Discussion of the inheritance of physical and mental characteristics may develop to include questions of 'moral' characteristics.

5.21 Genetic counselling is, then, concerned with prevention, but this unit, and Unit 14, ask just what it is that we can, and want to, prevent, disability or handicap? Genetic counselling can do valuable work to diminish the number of children with disabilities, but may not be able to attack prejudice or stigma which are just as damaging.

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6 *Conclusion: biology and special educational need*

6.1 In this unit I have argued that, while many disabled children rightly depend upon close contact with doctors, hospitals, and regular courses of drugs, and many teachers would benefit from a greater understanding of the biological basis of their pupils' disabilities, medical knowledge or expertise is not relevant to the education of the majority of children in special provision. The extension of a medical model to cover children with social and educational difficulties prevents constructive criticism of a system in which these difficulties arise and the search for alternative solutions to problems that remain intractable despite the proliferation of specialist services and 'treatments'. The medical approach focuses on sick individuals, rather than on institutions, defining handicap as if it was free from social influence.

6.2 The medical approach focuses on the prevention of disabilities rather than on changing the attitudes which make them handicapping. Overcoming handicap will not necessarily be facilitated by greater knowledge of the biological causes of disability, but the belief that this is so is still very widespread, and continues to influence people's approach to the understanding of children now labelled as 'autistic' or 'hyperactive', for example.

6.3 In Unit 1/2, Tony Booth argues that the kind of education system you support is a question of moral principle, not of educational 'science'. Any diagnosis of a biological condition is likewise an evaluation, and the use of labels like 'hyperactive' is a moral judgement about children. Labels are comparative judgements based on expectations of what is 'normal', 'healthy', acceptable, and not accurate accounts of what is going on inside a child's body. Also, biological knowledge of what *is* going on inside a child with physical or sensory disabilities is changing all the time, and in ways that are not reflected in the education system nor in popular opinion. This is particularly true when it comes to realizing that any group of children sharing a single identifiable disability, such as spina bifida or Down's Syndrome, is composed of individuals with very diverse abilities, disabilities, interests and problems.

6.4 What is to be the future role of the medical profession in the education system? Under the 1981 Education Act, local education authorities are 'required' to seek medical advice as part of the assessment of children thought to have special educational needs. Doctors will thus still formally be influential in the school careers of many children. Also, as, in theory at least, it is envisaged that many children for whom a 'statement' of special educational need is written as a result of multi-disciplinary assessment will be in ordinary schools, it is clear that a process of integration is not officially seen as rendering the form-filling obsolete, so doctors remain on the board of educational selectors.

6.5 The development of community health services, however, and of greater co-operation between health, education and social services, informally and at a local level, is a potentially more progressive change than the bureaucratic reshuffling of papers. (See Unit 16 for a discussion of the community school in the context of other community services, a comprehensive, non-hierarchical system on a manageable scale.) It remains to be seen how far the medical profession will be able to abandon the old categories of handicap for a definition of special educational need in terms of learning difficulty, and whether or not this will clarify their role in providing for children with disabilities. Barbara Bateman argues that:

> Medical classifications such as MBD are as irrelevant to educational practice as educational classifications are to medical practice. To ask which educational methods, materials, or techniques are most appropriate for children with MBD is analogous to asking which medications are best for children in the fastest arithmetic group or which dental techniques are best for children with auditory memory problems.
>
> (Bateman, 1974)

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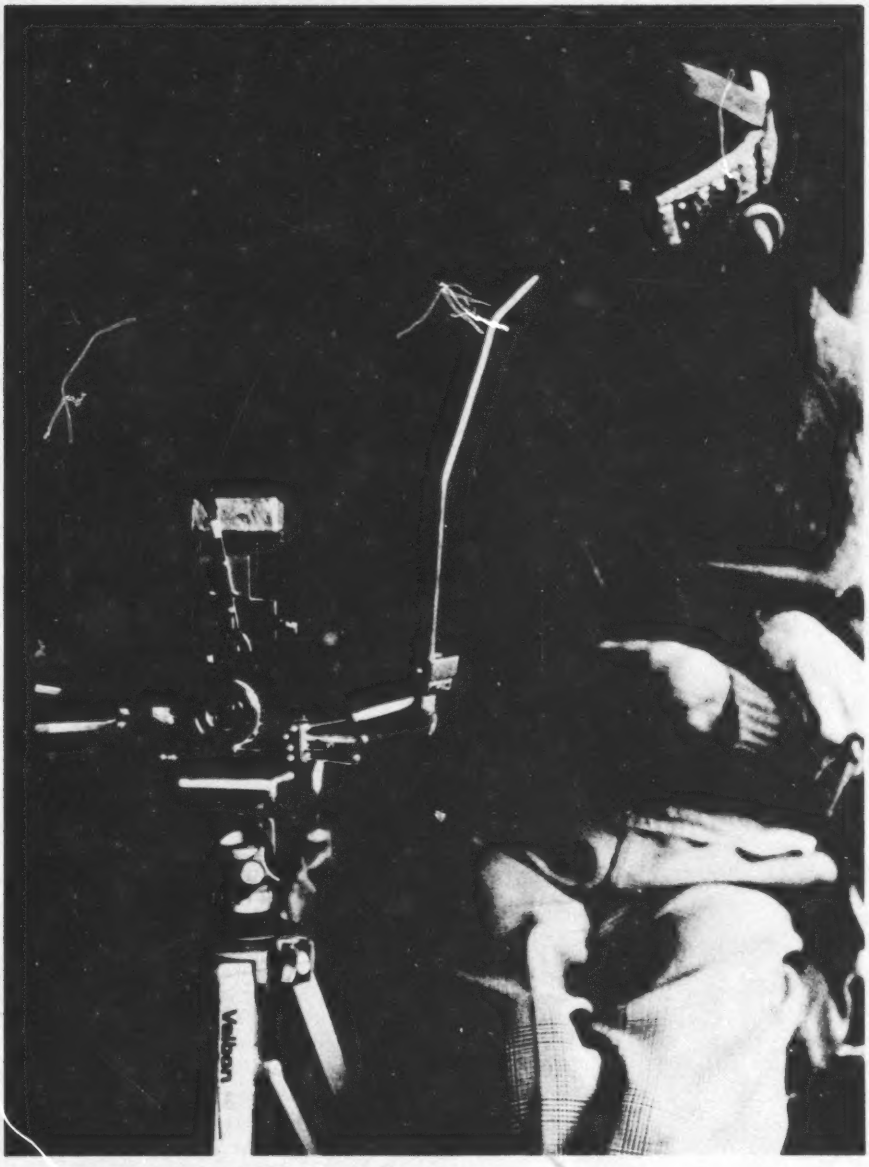
6.6 But finally, here is what the mother of a child who is mentally retarded, as a result of the mother's very mild bout of infection during pregnancy, has to say about official classifications and familiar labels:

> I feel awkward about the words I use to describe him. I've used 'handicapped', but that's through lack of a good alternative. When he's at school they'll call him sub-normal, or ESN, educationally sub-normal, the updated version. These are euphemisms for sub-human. At least he won't be officially listed as imbecile or moron, though no doubt he'll have to cope with these insults. I could call him backward, retarded, slow learner . . . Other people concerned with the issues have chosen 'people with disabilities', and I do want to identify with the politics of those who've chosen it. Yet when I say he's got a learning disability, I get blank looks, and I feel as if I'm denying the real differences. There's still a sense in which I feel the word 'handicapped' conveys the relation between my child and the world, while 'disability' seems more of a fixed concept, and a negative one, too.
>
> (Jane Elliot, *Spare Rib*, May 1981)



A severely disabled photographer.

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Unit 1/2
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Unit 3
Family views

Unit 4
Education for adult life?

Unit 5/6
A special curriculum?

Unit 7
The professionals

Unit 8
The powers that be

Unit 9
Origins

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National perspectives

Unit 11
Biology and handicap

Unit 12
Psychology and special education

Unit 13
Handicap is social

Unit 14
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Unit 15
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The author

Patricia Potts is a lecturer in educational psychology at the Open University. After graduating in modern history from Oxford in 1969, she trained as a teacher at the University of London's Institute of Education, as well as reading for a second BA (psychology and philosophy) from the University of London. She has taught at two ESN(S) schools in Brixton and Bethnal Green and as a remedial teacher in an ILEA child guidance unit, and also as a part-time Open University tutor for E362, *Cognitive Development*. In 1978–9 she was a full-time PhD student at the University of London—work which is continuing, but at a slower pace since her involvement with this course and the birth of her daughter, Joanna, in 1980.

For this course, she has also written Units 7 and 9, and is a co-author of Unit 16.

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